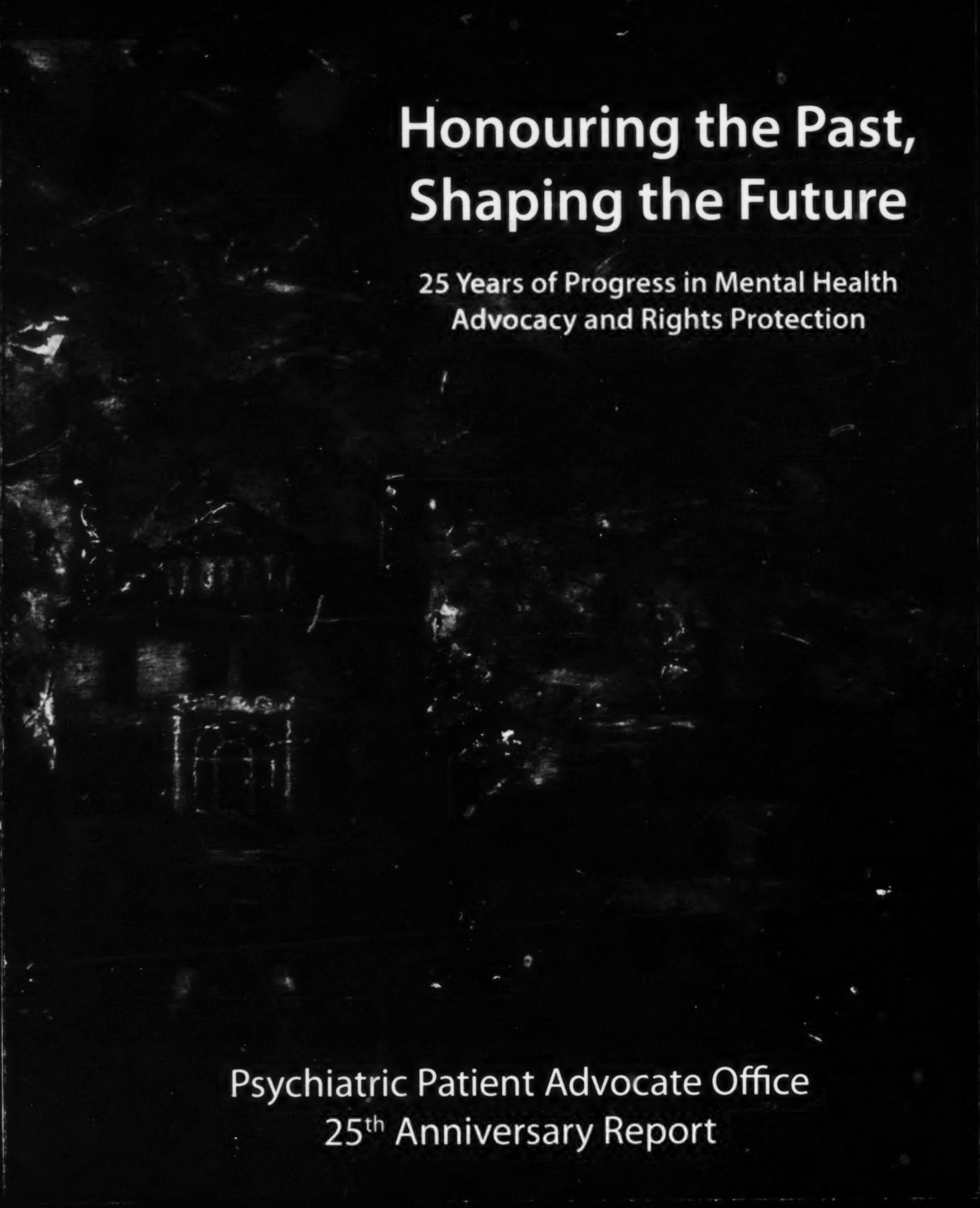

Honouring the Past, Shaping the Future

25 Years of Progress in Mental Health Advocacy and Rights Protection

Psychiatric Patient Advocate Office
25th Anniversary Report

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The articles included in *Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection* reflect the views of individual authors, and are not necessarily the views of the Psychiatric Patient Advocate Office nor the Government of Ontario. This publication is not intended to provide legal or other professional advice, and readers should seek independent advice as appropriate.

©Queen's Printer for Ontario
May 2008

ISBN 978-1-4249-6580-9 (Print)
ISBN 978-1-4249-6582-3 (PDF)

Additional copies may be obtained from:
Psychiatric Patient Advocate Office
55 St. Clair Avenue West
Suite 802, Box 28
Toronto, ON M4V 2Y7
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Cover: The Medical Exam Building, built in 1902 at The London Insane Asylum, is flanked by two patient dormitories — oil on canvas, Deanna Ronson, London Artist 1994, with permission.

Dedicated to people living with mental illness,
their personal journey towards recovery and wellness,
and the struggle to build a world where everyone is valued and belongs.

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ACKNOWLEDGEMENT

We wish to thank the authors who gave freely of their time and whose expertise, knowledge and personal experience is so clearly evident within the pages of this anniversary report.

We would also like to thank the production team, including: David Simpson, project manager; Lisa Romano, editor; Jim Ferry, cover design and book layout; Robin Rundle Drake, proofreader and Dorothy Bursey, administrative support. Without their hard work, enthusiasm and commitment this project could never have been realized.

We wish to recognize the tireless commitment of all of our staff, past and present, who over the past quarter century have built the Psychiatric Patient Advocate Office and helped to bring to life its vision of rights protection and advocacy.

Finally, we wish to acknowledge all those individuals and organizations that have diligently and passionately worked towards improving mental health services in Ontario.

FOREWORD

Michael Bay[*]

When I arrived in the world of mental health exactly twenty years ago it became evident to me that mental health involves a delicate balancing of rights. On the one hand we have the right of every citizen in a democratic society to autonomy and self-determination. On the other we find the right of every vulnerable person to safety, care and treatment and society's right to safety as well. The proper balance is difficult to achieve or even define. I frequently think of the never ending efforts to do so as attempts to reconcile the irreconcilable. Failure to maintain a constant struggle to find the point of equilibrium has dire consequences for individuals with mental illness.

I realized that the balance can be lost very quickly and individuals with a mental illness can lose their voice, their rights, and often their chance to receive optimal care unless they have skilled advocates and rights advisers acting on their behalf and on their instruction. Even the most loving family members and caring and skilled health professionals cannot replace an advocate acting for the individual. Without independent advocacy and access to rights protection mechanisms, individuals all too frequently have no voice and are lost in a system. And it is not just their civil rights that are compromised. Lack of a voice, lack of access to an independent advocate or rights adviser can easily result in less than optimal care, increased vulnerability, diminished quality of life, or the continued marginalization of the individual.

Ontario is respected around the world for the way that it has addressed the need for independent advocacy and rights advice. The Psychiatric Patient Advocate Office (PPAO), through its unique programme of instructed, non-instructed, and systemic advocacy gives voice to the voiceless and ensures that their wishes and needs are heard by treatment teams, other service providers, and policy decision-makers. For those who have their own voice, the PPAO supports them in their self-advocacy efforts and in achieving their desired outcome.

In the early days, the PPAO provided services only in the provincial psychiatric hospitals. Since 2001, the PPAO's mandate has expanded beyond those facilities to include provision of rights advice in many specialty psychiatric hospitals and general hospitals with mental health units. It also provides rights advice to people in the community who are candidates for community treatment orders and to their substitute decision-makers.

Mental health professionals, so resistive at the outset a quarter of a century ago, have come to recognize that the work of the PPAO has many positive benefits for their patients and their organizations. Policy makers benefit from the PPAO's experience and input and society is better off as the office has worked to create greater awareness of mental health legislation and patients' rights and to build a society that is understanding, accepting and inclusive of individuals with mental illness.

After twenty five remarkable years, I find it virtually impossible to conceive of a mental health system in this province without the PPAO. And it is not just the individual patients who would lose out. Ontario is recognized internationally for its mental health legislation and successful public policy. This is due in no small part to the vigilance and input of the PPAO.

In this comprehensive report, in celebration of the PPAO's 25th Anniversary, you will read articles written by consumers, families, advocates, lawyers, health practitioners, hospital administrators, judges, government officials, service providers and others who care for and about individuals with mental illness. Each author was identified as someone who has played a role in shaping mental health legislation and patients' rights in Ontario, in combating stigma and discrimination, in shaping public opinion with respect to mental health and mental illness, or for contributing positively to the mental health sector and our understanding as a society. Each article tells a story from a unique perspective.

May the PPAO's next 25 years be as successful as the last.

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[*] Michael Bay is a former Executive Assistant to the Minister of Health and Long-term Care, former Chair of the Consent and Capacity Board, and Associate Professor (PT) in the Department of Psychiatry at McMaster University. He is a frequent commentator on mental health issues in Ontario.

HONOURING THE PAST - SHAPING THE FUTURE: 25 YEARS OF MENTAL HEALTH ADVOCACY AND RIGHTS PROTECTION

Vahe Kehyayan*

In May 1983, the Ontario government launched the Psychiatric Patient Advocate Office (PPAO) as a provincial program intended to safeguard the rights and entitlements of patients in the provincial psychiatric hospitals (PPHs). From the beginning, there was clear recognition that those with serious mental illness were among our most vulnerable citizens. In part, this was due to the nature of their illness, but it was also the result of the way in which mental health services were provided and, in particular, the way in which the system disempowered those striving to make informed choices regarding their care, treatment and lives. With the publication of this special report, we celebrate a quarter of a century of mental health advocacy and rights protection, and the dedicated efforts of our program and staff in restoring decision-making authority to those we serve.

On our 25th Anniversary, it is natural to reflect on our past history, where we are now and where we are heading in the future. It is critical for us to examine the role of advocacy and rights protection in an evolving mental health and health care delivery system, in which the Ministry of Health and Long-Term Care will act as steward and Local Health Integration Networks (LHINs) will exercise regional authority in delivering health care services and allocating resources.

For the past 25 years, the PPAO has operated as an arm's length program of the Ministry. We have relied upon this "quasi-independence" as a fundamental ingredient in the delivery of advocacy services. It is our independence within the system we serve that is so highly valued by our clients and is a cornerstone of our credibility and effectiveness as advocates and positive agents for change. The PPAO's heart shaped logo, with its three divisions, places the patient at the centre with the advocate and patient's support network flanking either side. This corporate symbol graphically embodies our belief that the patient must always be at the centre of everything we do. Creating a caring and responsive mental health system depends on this fundamental premise and, in addition, requires the united and coordinated efforts of all stakeholders involved.

Despite safeguards enshrined in the *Mental Health Act*,[1] each year the PPAO continues to address a significant number of rights protection, quality of life and quality of care issues arising in the tertiary care psychiatric facilities that we serve. In 2007, we addressed 4,140 legal, therapeutic and social issues.

We are, with good reason, proud of our accomplishments of the past 25 years, achieved through the diligence and commitment of our staff, clients, psychiatric facility staff and other stakeholders. Our achievements to date are far too numerous to list, but the following examples provide some indication of the scope of the work of the PPAO:

- 1983: Provided advice to the Minister of Health that sections 66 and 67 of the 1978 *Mental Health Act*[2] should be proclaimed as a further step in the evolutionary process towards eventual compliance with the *Charter of Rights and Freedoms*;[3] those sections were enacted based on that advice;
- 1990: Made a submission to the Weisstub Report;[4]
- 1998: Launched a dedicated website[5] as an advocacy resource to all stakeholders and the general public; the website is widely accessed locally, nationally and internationally;
- 2000: Made a submission to the Standing Committee on General Government on Bill 68, *Mental Health Legislative Reform, 2000, and specifically advocated* for a requirement that patients being placed on a community treatment order receive rights advice;
- 2000: Developed a Minister approved training program to qualify rights advisers in accordance with the *Mental Health Act* and its regulations;
- 2001: Designed and implemented a community-based rights advice service to provide rights advice to patients in scheduled psychiatric units throughout Ontario and to individuals being placed on community treatment orders and their substitute decision-makers, if any;
- 2001: Issued a report and recommendations on "Seclusion and Restraint Practices in Provincial Psychiatric Hospitals in Ontario;"
- Ongoing: Publishes InfoGuides to provide information on a variety of rights protection topics and maintains a website to broaden public access to educational materials; and
- Ongoing: Continues to address a number of systemic issues, including: mandatory inquests for involuntary patients in psychiatric facilities, hospital management of patient funds, police record searches, the use of tasers, voting rights and psychotropic medication use in children and youth.

As system steward, the Ministry intends to focus on system leadership, accountability and performance improvement mechanisms, rather than the provision of direct services. In this context, the Ministry will need to examine the function, structure and place of advocacy within the health care system. The PPAO and many of its stakeholders believe that individual and systemic advocacy services should be integral to a comprehensive mental health system, and should be available to consumers regardless of where they receive their care, treatment, or rehabilitation services.

The importance of health determinants extending beyond the health care delivery system has long been recognized. Access to housing, education, employment and an adequate income are known to impact individual health in tangible ways. Similarly, feelings of self-worth and the ability to make autonomous decisions about one's life also have a significant impact on well-being and health care outcomes. For vulnerable consumers of mental health services, research suggests that "while biological characteristics cannot be modified, personal resources and environmental supports can, and they could have a considerable economic effect."[6] Thus, variations in an individual's personal resources or environmental supports can greatly alter the degree of their vulnerability or resilience, which in turn influences their use of health care services.[7] Advocacy may provide a means to modulate timely access to needed supports and reduce individual vulnerability

The benefits of individual, client-centred advocacy are well-documented. For example, one research study in the United States demonstrated that advocacy activities, which empower patients to voice their views about care and treatment and to make informed choices, have a positive impact on patients' quality of care and quality of life.[8] In this study, individuals with mental illness who were living in the community and receiving advocacy services experienced significantly fewer days of subsequent hospitalization than a control group which did not receive such services.

Currently, formal and informal advocacy services exist in Ontario through a variety of programs. However, these services appear to be fragmented and uncoordinated. In designing an advocacy model for the future, the PPAO and its stakeholders believe that advocacy services must be independent from service providers and provincially coordinated, with both a local and regional presence to ensure equitable access for all.

A provincial advocacy organization should include a number of core functions, such as: training and certification of advocates; setting practice standards for advocates; educating the public and professionals about mental health legislation and consumer rights; providing individual and systemic advocacy services; training rights advisers; and providing rights advice in psychiatric facilities and the community. Services could be delivered in partnership with stakeholders, consumer-survivor organizations, families and caregivers. Such an approach could serve to promote widespread collaboration on advocacy issues with the goal of improving the mental health system. The model envisioned would create a network of provincially coordinated, interconnected and complementary advocacy supports and rights protection mechanisms.

Such a rights protection mechanism would potentially offer many benefits to both consumers and the health care delivery system at large. For individuals, advocacy could help foster recovery and systemically support a recovery-oriented mental health system. For service providers, advocacy could contribute to an improved understanding of consumer rights issues. By assisting in early issue identification and intervention, advocacy could mitigate health care delivery risks for health care professionals and facility administrators. A provincial mechanism could support equitable access to services by providing the Ministry with a means to assess the availability, accessibility and quality of mental health services. An advocacy and rights protection mechanism could also serve as an independent check and balance within the system through ongoing monitoring of allegations of violations of consumer rights and entitlements.

Throughout this report, you will find evidence of change and progress, at times incremental and at times glacial in its pace. You will also find ample evidence in support of the continued need for broad-based advocacy and rights protection services. In shaping our future, we need to ensure that these services are integral to Ontario's mental health system. While we have made significant gains in patients' and consumers' rights over the past 25 years, there is so much more to accomplish. The collaboration of all stakeholders is pivotal in creating a client-centred system that is accountable to those it serves and giving persons with mental illness a greater voice in all aspects of mental health service delivery.

[*] Vahe Kehyayan has been Director of the Psychiatric Patient Advocate Office since August 1996.

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[1] R.S.O. 1990, c. M.7.

[2] R.S.O. 1978, c. 50.

[3] Part I of the *Constitution Act, 1982,* being Schedule B to the *Canada Act 1982* (U.K.), c. 11.

[4] Weisstub, D.N. Enquiry on mental competency: Final report. Toronto (ON): Queen's Printer for Ontario; 1990.

[5] www.ppao.gov.on.ca

[6] Browne, G. et al. (1999). Economic Evaluations of Community-based Care: Lessons from Twelve Studies in Ontario. Journal of Evaluation and Clinical Practice, 5(4), 367-385.

[7] Rogers, A.C. (1997). Vulnerability, Health and Health Care. Journal of Advanced Nursing, 26(1), 65-72.

[8] Freddolino, P. et al. (1989). An Advocacy Model for People with Long-Term Psychiatric Disabilities. Hospital and Community Psychiatry, 40(11),1169-1174.

HAPPY 25TH ANNIVERSARY, PPAO

Ty Turner*

The survival of the Psychiatric Patient Advocate Office (PPAO) after 25 years is a tribute to its vigorous advocacy and the many committed individuals who have been associated with the program, whether staff or volunteers. Nestled sometimes uncomfortably within the Ministry of Health and Long-Term Care, the PPAO has survived heavy criticism (during the early 1980s), restructuring (early 1990s) and budget cutbacks (mid 1990s). Along the way, the program has gathered strong support from both inside and outside of government. To a large extent, this has reflected the program's adherence to a clearly drawn mandate to protect the legal rights of mentally ill persons, undertaken with competence and professionalism. The PPAO can be credited with the frequently made observation that mentally ill people in Ontario enjoy greater rights protection than any other province and probably most American states. The Ontario *Mental Health Act,*[1] *Health Care Consent Act*[2] and *Personal Health Information Protection Act*[3] place a high level of protection over the liberty and autonomy of mentally ill individuals, whether this involves civil commitment, consent to treatment or access to personal health information. Beyond these central issues, the PPAO made a major contribution towards Ontario becoming the first province to establish voting rights for hospitalized psychiatric patients. The PPAO showed that patients voted for political parties in the same proportion as the general population. More recently, the program has articulated the patients' perspective on Ontario's restrictive smoking laws, which many believe place unfair restrictions on the quality of life of institutionalized psychiatric patients. Amongst other issues, the PPAO has also addressed the use of restraints, housing policies and tasers.

In addition to its direct advocacy, the PPAO has had a major educational impact on Ontario's mental health system. Viewed as a constitutional necessity, the PPAO's rights advisers have provided person-to-person rights information to thousands of individuals who have been committed to psychiatric facilities, or deemed incapable of making their own decisions. They have assisted countless numbers of people to retain counsel and challenge professional decision-making at the Consent and Capacity Board. Rights Advisers have become acknowledged as experts in linking constitutional protections to their rightful recipients, a role which they have performed with effectiveness and sensitivity.

In the larger picture, the PPAO has behaved as a cultural catalyst, not just because of what it says and does, but how it behaves. In large psychiatric facilities and beyond, we no longer tend to see battles over the rights of psychiatric patients or whether advocacy interferes with treatment and recovery. The argument has been made, and won, that the enjoyment of rights by mentally ill individuals often promotes treatment and recovery as patients, knowing their rights, have a voice and consequent involvement in decision-making. Individual treatment plans are now more likely to be negotiated. Patients more frequently feel as if their issues have been addressed, and thus are invested in their recovery plans. This leads to higher rates of treatment adherence and, in a larger sense, engenders personal responsibility and citizenship. In my opinion, as a practicing psychiatrist in various hospitals over the past 18 years, this greater involvement of patients in clinical decision-making has occurred in a smooth and almost seamless way. This sort of transformation has reflected a true cultural shift, and while its causation is complex, the PPAO deserves some of the credit. Further reflecting positive change, some make the observation that, beyond a few amendments in 2000, there has been no groundswell pushing for change in Ontario's mental health legislation over the past 20 years.

To a major degree, the mental health field has moved on. This represents a major challenge to the PPAO, whose mandate was developed in the later stages of the civil rights era and during a period when Canada had just patriated its constitution, incorporating a new *Charter of Rights and Freedoms*,[4] leaving Ontario's mental health legislation vulnerable to *Charter* challenges. Accordingly, the founding of the PPAO was very much grounded in the *Charter's* imposition of more stringent safeguards over legal rights.

While legal protections continue to be important, much has changed since the early 1980s. With major changes in the health care system, large provincial psychiatric hospitals have been devolved to their own, non-profit boards, thus minimising government and public control. The health system has now become regionalized with 14 Local Health Integration Networks (LHINs) covering all areas of the province. Hospitals have been closed and there has been a further reduction of psychiatric beds, particularly harsh when taken against the growth and aging of Ontario's population. While the traditional legal advocacy role of the patient advocate is principally rooted in inpatient care, more than ever, most psychiatric care is not delivered in hospitals, but in community settings, such as family doctors offices, community agencies, jails, probation offices and homeless shelters. However, psychiatric patients' access to health care is being threatened. As an example, on the medical side, evidence shows that the greatest proportion of patients receive treatment through primary care physicians, and not psychiatrists. To a certain extent, psychiatric patients have become dependent on general practitioners for both their physical and mental health care. Often they have complex health needs, because of high rates of diabetes, high blood pressure, obesity and heart disease coexisting with mental illness. There are many other illnesses which are found more commonly amongst mentally ill persons than in the general population, contributing to significantly shortened life expectancy. Yet, with the increasing shortage of general practitioners, many have been unable to find doctors and have joined the expanding ranks of "orphan patients," without either primary care physicians or nurse practitioners. Furthermore, Ontario's Primary Care Reform creates new disincentives for primary care physicians to open their practices to mentally ill patients.

In future, how will mentally ill individuals be able to access primary care for their many physical health issues, as well as psychiatric ones? Accordingly, the conversation has shifted from rights to entitlements. Advocates will be limited if they continue to focus on the traditional legal rights of liberty and security of the person, since they have been largely interpreted as safeguarding the avoidance of unwanted treatment. But what about the much more common situation where the person wants treatment, but is unable to access it, because of a disadvantage, such as a mental illness? In this time of increasing scarcity of health resources, the case can be made that mentally ill individuals are becoming increasingly disentitled to good quality health care. While there are already many strong advocates for housing, employment and income supports, who will advocate for access to health care? In times like these, we need the PPAO to help articulate the voice of the consumer, which can be easily be drowned out in the cacophony of interests which accompanies major system change.

My best wishes to all the staff and supporters of the Psychiatric Patient Advocate Office and congratulations on a quarter of a century of setting the pace.

*Dr. Ty Turner, MD was the founding Provincial Coordinator of the PPAO (1982-1986) and is currently, the Chief of Psychiatry, St. Joseph's Health Centre, Toronto.

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1 R.S.O. 1990, c. M.7.
2 S.O. 1996, c. 2, Sched. A.
3 S.O. 2004, c. 3, Sched. A.
4 Part I of the *Constitution Act, 1982,* being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

THE HONOURABLE LARRY GROSSMAN: FOUNDING FATHER OF THE PSYCHIATRIC PATIENT ADVOCATE OFFICE

Ted Ball*

Respect, compassion, dignity, human rights, and community service were values that were instilled in Larry Grossman by his family from the start. Mr. Grossman would recall how, as a young boy waking up each morning, he would hop out of bed and tiptoe around refugees who had been taken in for the night by his parents in the aftermath of the 1956 Hungarian Revolution. He understood what was expected of him: he was to "add value" to the world by being in service to the communities of which he was a part.

As a cabinet minister, Mr. Grossman was visionary, highly strategic and courageous. He was determined to make a difference in the world that he inherited. When he arrived as Minister of Health in 1981, Mr. Grossman was clearly a star cabinet minister in the government of Bill Davis. He had already proven himself to be innovative and bold as the Minister of Industry in his efforts to support the transformation of Ontario's economy from its traditional industrial base to the underpinnings of what has now evolved into the knowledge economy.

By his third day as Minister of Health, Mr. Grossman had exchanged his pinstriped suits for blue jeans and a T-shirt as he toured Parkdale with ex-psychiatric patient activist, Pat Capponi, who today is a successful Canadian writer.

Pat Capponi did not give Mr. Grossman a nice safe ministerial tour. In the late 1970s, the provincial government had closed thousands of institutional psychiatric beds – in part due to budget constraints, in part due to changing treatment patterns – but they had no, or very few, support programs in the community.

Releasing thousands of patients with only a packet of pills and a pat on the back had produced a major crisis in downtown Toronto. Deplorable living conditions and what coroner juries called "death by therapeutic misadventure" were the results of government policies that had no vision and no strategy for the traditional "poor cousin" of Ontario's health care system: the mental health care sector.

Shaken by Pat Capponi's real-world tour of Parkdale's Kafkaesque boarding houses, and by his conversations with the ex-psychiatric patients he met, Mr. Grossman vowed he would transform the provincial mental health system – and in particular, to provide dignity, respect, and meaningful support for those who needed it, where they needed it.

As he dug deeper and learned more about mental health issues over his first several months at the Ministry of Health, Mr. Grossman began to develop a much more comprehensive approach that was based on the advice of the mental health reform advocates with whom he surrounded himself.

Steve Lurie, Aileen Meagher, Brian Davidson, Mary Ellen Polack, Ron Ballantyne, Tyrone Turner, and numerous front-line support workers collaborated with Mr. Grossman and his staff to craft policies and programs that would enable the system to evolve to meet the changing needs of the people it was intended to serve.

Within 18 months of his arrival at the Ministry of Health, Mr. Grossman had spearheaded: major reforms to the *Mental Health Act* which focused on patients' rights; the creation of the Psychiatric Patient Advocate Office (PPAO); and the expansion of community-based mental health and support programs that sky-rocketed from a budget of $12 million to $54 million per year.

But what Mr. Grossman understood was that money and laws alone would not fix the system: what was needed was a fundamental shift in the way we think about mental health – both within the mental health system itself and within the public.

For the public, Mr. Grossman, through his partnership with the provincial arm of the Canadian Mental Health Association, sponsored large-scale award-winning radio and television commercials that appealed for public support for the reintegration into the community of fellow citizens who had experienced a mental health problem.

Mr. Grossman understood that the real struggle for shifting attitudes would be in the mental health care system itself – among administrators and mental health professionals. That is why he placed special emphasis on the role of the PPAO as the key leverage point in the system. Mr. Grossman wanted the PPAO to have a profound impact on the culture that had evolved within the system.

"Our challenge," said Mr. Grossman, "is to change the very culture of the system. We need to help administrators, professional practitioners, and Ministry of Health officials to change the way in which they think about mental health and patients' rights."

His strategy for shifting an ingrained way of thinking about mental health included:

- creating a new Division for mental health within the Ministry, and appointing Dr. Boyd Suttie as the Assistant Deputy Minister for the new mental health division – *at the same management table as the* Assistant Deputy Ministers for hospitals and OHIP payments;
- recruiting a new breed of chief administrators for most of the 10 provincial psychiatric hospitals within a year; and
- recruiting Dr. Tyrone Turner to be the first Director of the PPAO.

While Mr. Grossman had the full support of his cabinet colleagues for his mental health reforms, the appointment of Dr. Turner – a former NDP candidate – did provoke some negative feedback from the Tory cabinet minister who had beaten Dr. Turner in the previous election. But Mr. Grossman held firm. He believed that it was essential to ensure the independence of the office – which he believed Dr. Turner's appointment achieved.

With his new stature as a senior Director in the Ministry of Health bureaucracy, Dr. Turner was able to work with the full cooperation of Deputy Minister Graham Scott, Assistant Deputy Minister Boyd Suttie and fellow Director, David Corder, to set up the initial systems, structures, and processes that would achieve a fundamental shift in the way the system and the people in it understood "patients' rights."

So, here we are – 25 years later. Did the PPAO achieve its intended purpose? Did Larry Grossman's mental health reform strategy work?

As someone who worked with Mr. Grossman on his various strategic initiatives, I feel close enough to his thinking to say that if Larry were alive today, he would be very proud of the people from Tyrone Turner to Mary Beth Valentine to Vahe Kehyayan – and all the people who worked for them – who made his vision come true.

I can also, with some confidence, predict that if Mr. Grossman were with us today, immediately after applauding and celebrating everyone who had contributed to the success of the PPAO, he would ask the following probing questions:

- Are we as consumer/survivor-focused as we ought to be?
- Are we truly accountable for designing and delivering services that are grounded in the perspectives of consumer/survivors? and
- If the program has proved itself in the former provincial psychiatric hospital system, why isn't it available to the people who need these supports – wherever they are in the health care system?

He would remind us of the core values that must drive our thinking and behaviour – the values of respect, compassion, dignity, community service, and human rights. Then he would explain to us how in fact … we could be doing much better!

We should have advocacy for individuals with mental illness who are using or trying to access mental health services anywhere in the system and who need the help of a professional advocate to help them navigate the system – independent of system managers, service providers, and policy-makers. Such services should range from focusing on individual issues to addressing systemic ones – including system design, monitoring and evaluation – all from a consumers' perspective.

Knowing Larry, those would almost certainly be the types of probing questions, universal values and "pushing of the envelope" that my dear friend and former boss would talk to us about at PPAO's 25th anniversary celebration. And these are the things that the mental health community, the Ministry of Health and Long-Term Care, and the PPAO must continue to ask themselves as they work to continuously improve the mental health care delivery system.

[*] Ted Ball was Larry Grossman's Chief-of-Staff and Senior Policy Advisor at the Ministry of Labour, the Ministry of Health and Ministry of Finance. Today, he is a partner in Quantum Transformation Technologies – an innovative firm that helps organizations to develop their own internal capacity to redesign themselves as customer-focused service providers.

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POSTCARDS FROM THE PAST

Richard Costello[*]

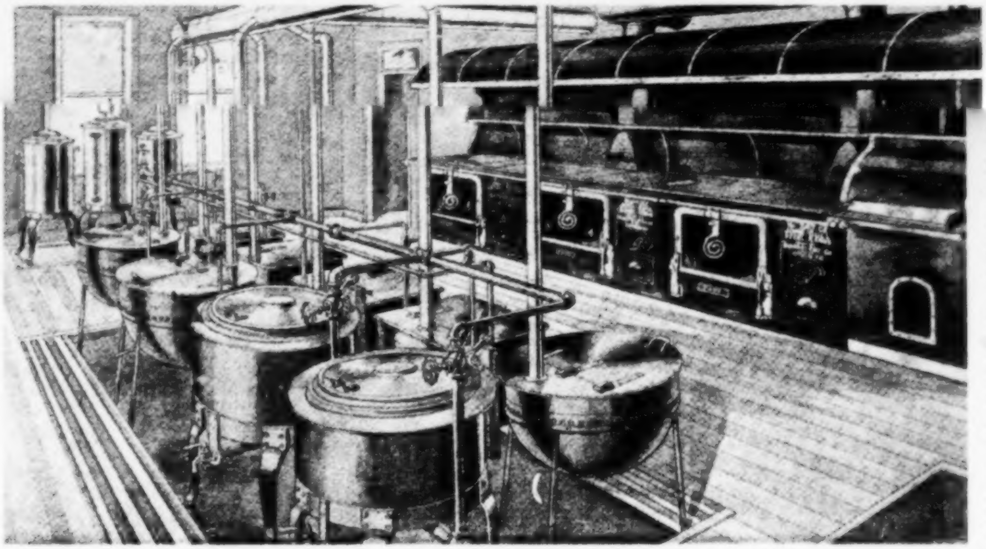
INSANE ASYLUM, KINGSTON, BEAUTIFUL SPOT.

A Beautiful Spot, 1906 (author's collection)

Mental health care of 100 years ago employed more than a few terms and practices that we would find intolerable today. "Idiot," "imbecile" and "stupid" described levels of intelligence. "Degenerate," "lunatic" and "maniac" were terms of diagnosis. But doctors and patients alike were agitating for change to the monolithic warehouses that were government asylums.

I am a rights adviser in the general hospitals of downtown Toronto. From collecting postcards of the old asylums of Ontario, I've become curious about what asylum life was like a century ago.

1907 was a pivotal year in Ontario – "asylum" became "hospital," scientific patient casebooks were established and training for mental health nurses was formalized. The worldwide trend to put things on a "scientific" and "efficient" basis was beginning to carry over into asylums.



The New Kitchen at Cobourg Asylum, 1906 (author's collection)

But it's been well documented, particularly by Dr. Geoffrey Reaume,[1] that the veneer of respectability and humane treatment covered widespread abuses. Patients, under the pretext of "moral treatment" worked to "earn their keep."

> "A roadway (has been built) from near the west side entrance to the Superintendent's residence, the bed of which was formed of large stones removed from the grounds…"[2]

Now, there is nothing for clients to do. Over and over I have been told how boring it is, how it's "driving me crazy being in here."

Staff were also poorly treated, and highly transient because of it.

> "Whenever a physician enters the ward, all the nurses and attendants shall rise.
>
> All nurses, attendants and employees must be ready to perform temporarily on holidays, or when called upon by the Superintendent, any extra or unusual duty that may be assigned them, and without extra remuneration."[3]

> "Our greatest difficulty has been in keeping up the staff of attendants, nurses and domestics. The general demand for labor is so great that we find it difficult to compete successfully in the labor market. There seems only one remedy, and that is to increase the remuneration in the hope of attracting a better class of applicants…"[4]

It was not until some years later that the Superintendent's residence at the Toronto Asylum was renovated as a residence for female nursing staff. Until then attendants had slept in the ward next to the patients.

Today of course, staff don't live at the asylum. Instead, they are contained behind glass walls that completely remove them from the patients. I have seen a newly renovated unit with a nursing station built so that nurses and doctors look out the window and have their backs to the patients. Under the label of "safe and secure," patients and staff live in two separate worlds.

Nurse's Residence, Toronto Hospital for the Insane, 1915 (author's collection)

In 1907 patients had no advocates, unless relatives were unusually persistent in their efforts. But there was no question of who was in charge:

> "…After keeping him here some time we will then decide if he is fit to be at large, and if so, I will recommend his discharge."[5]

Relatives were very much in the thrall of the doctors in 1907 – who but the superintendent knew what to do with a mentally ill relation?

> "We feel so grateful to you for your kindness to (patient). I always had a dread, in fact, a horror of homes like the one you are over, but will never feel like that again, for (patient) calls it her home and talks with pleasure of the time when she will visit you."[6]

Even the most difficult news was delivered matter-of-factly, if not coldly. The following is an example of a telegram sent to a patient's husband:

> "Dear Sir:
>
> M. W. is dead. Please arrange for burial.
>
> Dr. William English, May 3, 1913. Hamilton."
>
> (Noted at the bottom of the telegram: "sent collect")[7]

There was no separate question of capacity when a person was committed – a doctor prescribed as he felt necessary, when and where he chose.

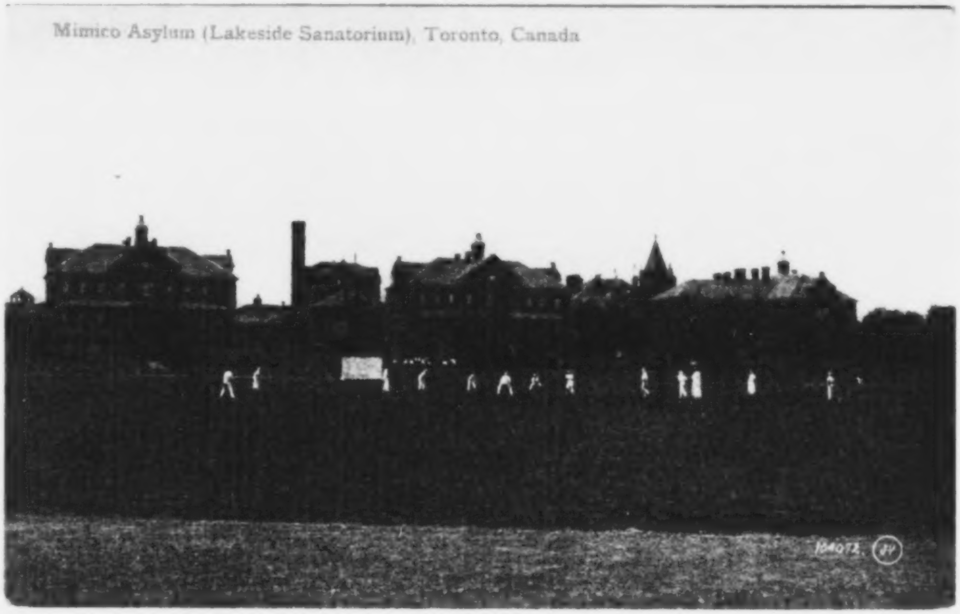
Treatments were of a variety that would seem very strange today. Hydrotherapy was widely used:

> "Slept well the first night, but had a hypnotic. The next night she was very restless. She was then placed in the continuous bath and kept there for treatment for about 12 days."[8]
>
> The Sheet Bath
> "Wrap the nude patient in a blanket, bathe face and head in cold water, fasten an iced turban on the head. Another attendant drops one sheet lengthwise into the tub of water...Wring out the sheet. Spread it on the bed rapidly…Quickly lay the nude patient on the wet sheet with arms above the head…covering the shoulders, arms and lower extremities…"[9]

Treatment was also very odd. Moreover, informed consent was not considered important.

> "In melancholia and alcoholic insanity, opium and its alkaloids are valuable…Either morphine or codein (sic) may be given hypodermically, but the latter, I think, is preferable. I need hardly say that in no case should the patient be told the name of the drug employed."[10]

The Toronto Star in October of 1907 reported the results of an inquest into the death of James Robinson, who had been an inmate at Mimico. Relatives had removed him from the asylum when they visited and found him bruised and suffering from a broken rib. The jury ruled that his injuries had resulted from "repeated falls against his bed," and that his death was a result of "general paresis" in spite of evidence given by his widow about the fear her husband showed in the presence of the guards. All three of the attendants in charge of Robinson declared him "obstreperous and requiring a great deal of attention."[11]



Mimico Asylum (Lakeside Sanatorium), Toronto, Canada

David Gibson, an inmate of Mimico Asylum since 1905, petitioned the Chief Justice of Ontario for his release, on the grounds that he was not insane, but rather epileptic. Gibson's lawyer pointed out to the Toronto Star that "many hundreds of epileptic cases were treated privately, and that he considered it an outrage that Gibson should be confined in Mimico."[12]

A new hearing was ordered before the Court of Appeal, which turned on the issue of Gibson's sanity.

> "Do your lordships think that a public institution in this country would keep a man confined unjustly?" asked The Deputy Attorney General, as prosecutor.

> "Asylum officials are just as liable to err as anyone else" sharply remarked the judge.
>
> "But they are experts in insanity cases" said the Deputy Attorney General.
>
> "There's a danger in that too, some people think" replied the judge.[13]

Gibson was not released.

Now we have the Consent and Capacity Board to guard against unnecessary confinement. But I have seen a person put on a Form 3 immediately after attaining their voluntary status – on the merits, not on a technicality – at a Consent and Capacity Board hearing.

I have seen what I call "The Shuffle" – Form 1, Form 3, Form 16, Form 5, Form 1 – more times than I can count. A patient is brought into the hospital on a Form 1. He or she is then placed on Form 3 (involuntary status of up to 2 weeks) and given rights advice. They apply to the Board on a Form 16 (application to review a finding of involuntary status) which miraculously causes a Form 5 (voluntary status) to appear on their chart. When the client attempts to leave the hospital, however, they are promptly re-formed, and the shuffle starts again. How many voluntary patients have I seen who can't leave?

Today we have patient advocates in all of the former provincial psychiatric hospitals. But there are more people confined in general hospitals than in the former provincial psychiatric hospitals, and many more than that subject to the many headed monster that is the community treatment order. There are no advocates for those who "agree" to sign away their privacy in exchange for release from hospital.

Which begs the question – in 2107, which of our current practices and beliefs will be looked upon as barbaric? Electric shock? Forced treatment? Community treatment orders?

I have given rights advice to a woman who had had her arm broken by security. When I enquired about it, the doctor said "what business is it of yours?"

I have seen a man so badly beaten by police that the attending psychiatrist asked me to do something about it. So badly beaten that the cops had refused to fill out an Emotionally Disturbed Patient form or give the hospital intake workers their names.

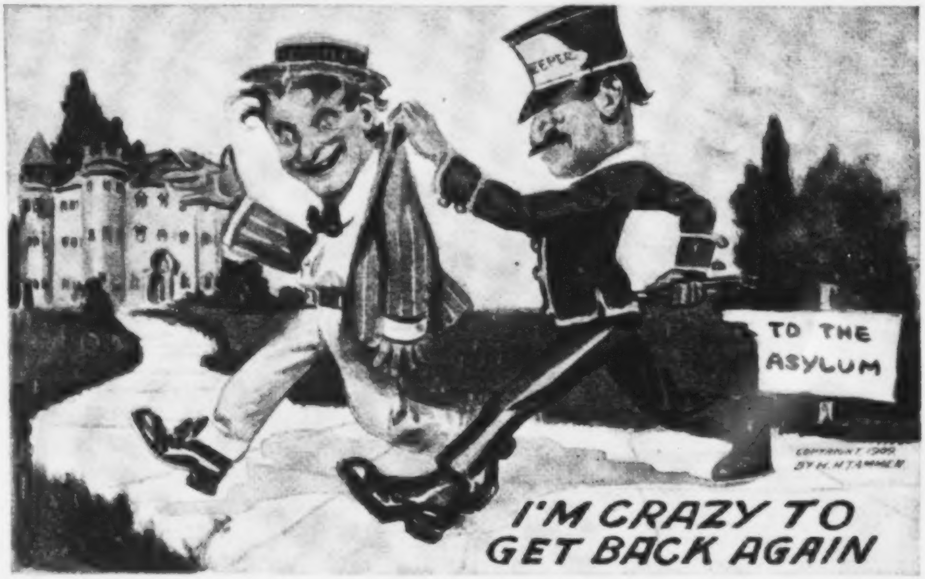
I have seen a man kept in a locked room for a month, only allowed out to shower while accompanied by security, because he has a history of violence. Not because he was *being* violent, but because he had a "history."

I have seen nurses "withhold privileges" to force a patient to modify their behavior. The privilege withheld was calling their lawyer.

I have seen a child of 13 in four point restraint.

Time and again I have wanted to yell "you can't do that", but I don't. Because they can, and they do and I'm not allowed to do anything.

Maybe we should call 1907 The Good Old Days.


EEPER
TO THE ASYLUM
I'M CRAZY TO GET BACK AGAIN

*Richard Costello is a rights adviser with the Psychiatric Patient Advocate Office who started collecting postcards as a therapy for depression. Postcards of old Toronto and the Asylums of Ontario have since become an obsession for him, of which he hopes someday to be cured.

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[1] Reaume, Geoffrey. *Remembrance of patients past : patient life at the Toronto Hospital for the Insane, 1870-1940.* Don Mills, ON: Oxford University Press, 2000.

[2] Thomas Moher, Superintendent, Brockville Asylum in *Annual Report of the Inspector of Prisons and Public Charities upon the Hospitals for the Insane, Idiotic and Epileptic for 1907.* Legislative Assembly of Ontario, 1908, p.142. MS 2100, Archives of Ontario.

3 *Official Rules and Regulations For the Guidance of Officers and Employees in the Provincial Hospitals for the Insane, etc. (revised 1905)* Toronto: Clarkson James, 1922.

4 G.A MacCallum, Superintendent, London Asylum in *Annual Report of the Inspector of Prisons and Public Charities upon the Hospitals for the Insane, Idiotic and Epileptic for 1907.* Legislative Assembly of Ontario, 1908. p.32. MS 2100, Archives of Ontario.

5 Casebook 4501, Hamilton Asylum, March, 1905. Hamilton Psychiatric Hospital patients' clinical case files RG 10-285 Box 136012, Archives of Ontario.

6 Casebook 4953, September, 1907. Hamilton Psychiatric Hospital patients' clinical case files RG 10-285 Box 136012, Archives of Ontario.

7 Casebook 4546, May 3, 1913. Hamilton Psychiatric Hospital patients' clinical case files RG 10-285 Box 136012, Archives of Ontario.

8 *Casebook 364* Brockville Psychiatric Hospital patients' clinical case files RG 10-308 Box 181630 Archives of Ontario.

9 Barrus, Clara, Nursing the Insane. New York : Macmillan, 1908. p. 97.

10 Burgess, T.J.W.. "The Family Physician and the Insane". The Montreal Medical Journal James Stewart et al. eds. [Vol. 36, no. 2 (Feb. 1907): p. 104

11 "Asylum Guards Not to Blame" Toronto Star, October 23, 1907, p.1

12 "Pleads for Release From Mimico Asylum" (Toronto Star, July 16, 1907, p.1).

13 "Doctors Can Err, Said the Judge" (Toronto Star, September 23, 1907, p.1).

REFLECTIONS ON THE CONSUMER/SURVIVOR/EX-PATIENT (C/S/X)

David Reville*

The c/s/x movement is not a centralized national movement with well-defined leadership, membership, goals and objectives. It has no official leaders, no official hierarchy and no ongoing organizational structure. Rather, it exists as a loose coalition of advocacy and activist groups whose members engage in numerous activities designed to promote mutual support, rights protection, alternatives, advocacy, and information flow that will enhance empowerment and choice for people whose lives have been affected by psychiatry.

> -Linda J. Morrison, *Talking Back to Psychiatry: The Psychiatric Consumer/Survivor/Ex-Patient Movement*[1]

When I'm telling my students[2] at Ryerson about the c/s/x movement, I screen a documentary called *Mental Patients Association.*[3] Every time I watch it, I have a "what if?" moment. What if we had stayed in Vancouver two more weeks? We might have been at the founding meeting of the Mental Patients Association (MPA) and our lives might have been quite different. Instead, we were back in Toronto in mid-January 1971 and missed out on the birth of the Canadian c/s/x movement.

I didn't hear about the MPA until Don Weitz, self-styled "Schizophrenic" Shit-disturber, came back from an eleven day visit in 1973 and said "I've got to find some people to start something like MPA."[4] And he did, in 1977, when 150 people turned up at All Saints Church, at the corner of Dundas and Sherbourne. On Our Own[5] was a tremendously successful self-help group that operated until 1997. During that time, On Our Own ran a drop-in, operated a store called The Mad Market and published an anti-psychiatry magazine called *Phoenix Rising: the voice of the psychiatrized.*

The growth of the movement was slow. A directory[6] put together in 1986-87 listed just nine groups in all of Canada. In 1991, however, the Ontario government announced a $3 million project called the Consumer Survivor Development Initiative (CSDI). CSDI provided funding to 42 self-help organizations. What had started as a one-time anti-recession project is now built into the province's mental health budget. The $3 million has grown to about $10 million. Yet, in spite of the fact that "consumer-run" initiatives were declared a "best practice,"[7] Ontario remains the only province to provide significant funding for them.

One project of the c/s/x movement was to create alternatives to the mental health system. The Mad Market was an early example of an alternative to the sheltered workshops and industrial therapy that we found to be so demeaning. Starting out in a stall in a flea market, the Mad Market got some community economic development money from the city of Toronto and opened a store in the east end. In Simcoe, several rakes purchased with a federal grant got Abel Enterprises going; today it produces custom woodworking. Last year, A-Way Express celebrated its 20th anniversary. All 65 of its employees, from Executive Director to trainee courier, are psychiatric survivors. "Survivor-run" businesses employ about 800 people – people who used to be described as "permanently unemployable."[8] After the release in 1999 of the National Film Board documentary "Working Like Crazy,"[9] the story of survivor business in Ontario has travelled around the world. Following a screening in Taipei City, the documentary now comes with Mandarin subtitles.

From the beginning, there has been tension between those who wanted to develop alternatives to the system, those who wanted to change the system and those who wanted to bring the system down. The Ontario Psychiatric Survivors Alliance, established in 1990, never resolved that tension.[10]

The mid-80s saw the rise of "consumer participation." The Canadian Mental Health Association-National (CMHA), for instance, established its Consumer Participation Task Group in 1987. Toronto City Council was out in front of CMHA by several years[11] when it appointed Pat Capponi to the advisory committee of the Mayor's Action Task Force on Discharged Psychiatric Patients. PPAO historians will know that Pat co-chaired (along with Dr. Bob Buckingham) its advisory committee for many years. Today, Pat is a member of the Saving Lives Implementation Group[12] as, eleven years after the shooting of Edmund Yu, psychiatric survivors continue to try to influence the way in which the police respond to people in crisis.

What's next for the c/s/x movement? There's buzz around "recovery" and the potential for survivors to take on peer support roles in the system. The system itself is taking cautious steps towards hiring more people with psychiatric histories. Survivor leader Diana Capponi has taken a job in the human resources department at the Centre for Addiction and Mental Health to ensure that it does not lose its resolve. Survivors are involved in the National Mental Health Commission and will be working to influence its direction and activities. Canadian survivors will continue to develop connections with survivors in other parts of the world. Inspired by the Psychiatric Survivor Archives of Toronto, a user group in Edinburgh, Scotland sought and obtained funding to develop an archive of its own. There's a small but growing number of survivors doing post-graduate work and these "high-knowledge-crazies" will bring new knowledge to the movement. Many of them will travel to Vancouver this spring to give papers at the Madness, Citizenship and Social Justice conference.[13] The movement is being strengthened and changed by the advent of younger people. Last summer on Mad Pride Day,[14] I was excited to see a number of Mad Students, members of a group started by Lucy Costa,[15] providing peer support, advocacy and self-empowerment for students experiencing "mental health" issues in post-secondary institutions. Already they're changing the conversation. As one Mad Student explained it, using the word "mad" is a political way in which those who have been psychiatrized can take back language that has been used to oppress them. "Psychiatric survivor" excludes a newer generation of people who have not experienced the long-term institutionalization and abuse that was common in the past."[16]

Students in my Mad People's History course handed in their book reports on February 28th. They chose from a list of 25 books, each of which had been written by a psychiatric survivor. One of the students reviewed Pat Capponi's *Beyond the Crazy House: Changing the Future of Madness.*[17] Pat tells how she and eleven other survivors figured out what they needed to do to get beyond the sick role they'd been assigned by the mental health system. At the end of the book, Pat reflects on the accomplishments of the people she'd been working with and the survivor movement as a whole:

> *...on most days I'm filled with a deep sense of pride and shared accomplishment. We are survivors, and more than just survivors: we are groundbreakers and role models and teachers and leaders. And though there remains much to do, much to fight, much to plan, we have made a tremendous start, for ourselves and for others. Madness will never be the same.*[18]

Amen to that.

*David Reville is an instructor in the School of Disability Studies at Ryerson University and a psychiatric survivor.

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[1] Morrison, L.J. *Talking Back to Psychiatry: The Psychiatric Consumer/Survivor/Ex-Patient Movement* (2005) New York: Routledge, p. 57.

[2] With Jim Ward, we team-teach A History of Madness four times a year and, on my own, I teach Mad People's History once a year.

[3] National Film Board (1977).

[4] Weitz, D. "Notes of a 'Schizophrenic' Shitdisturber" in Burstow & Weitz (eds.) *Shrink Resistant: the struggle against psychiatry in Canada.* (1988) Vancouver: New Star, p. 290.

[5] Chamberlin, J. *On Our Own: Patient-Controlled Alternatives to the Mental Health System* (1998) New York: McGraw-Hill.

[6] The Psychiatric Inmates' Liberation Directory in *Shrink Resistant*, p. 328.

[7] Clarke Institute of Psychiatry, Health Systems Research Unit, *Best Practices in Mental Health Reform*

[8] Dr. Kathryn Church, associate professor in the School of Disability Studies at Ryerson, is *the* authority on survivor business. Many of her books and articles are available on-line.

[9] Directed by Gwynne Basen and Laura Sky.

[10] Irit Shimrat recounts OPSA's history in her book *Call Me Crazy: Stories From the Mad Movement* (1997) Vancouver: Press Gang.

[11] May 16, 1983.

[12] *Saving Lives: Alternatives to the Use of Lethal Force by Police* is the report of a conference held in Toronto in June, 2000. The conference was organized by the Queen Street Patient Council and the Urban Alliance on Race Relations.

[13] June 12 - 15, 2008 at Simon Fraser University.

[14] July 14, 2007.

[15] Lucy's day job is with the Empowerment Council at CAMH.

[16] Jenna Reid, "Response Paper 1: The Dimensions of Disability Oppression" (2008)

[17] Capponi, P. *Beyond the Crazy House: Changing the Future of Madness* (2003) Penguin: Toronto.

[18] *Ibid*, p. 232.

"ANCIENT HISTORY"? THE RELEVANCE OF THE PAST TO THE PRESENT IN ONTARIO'S PSYCHIATRIC HISTORY

Geoffrey Reaume *

In January 2006 during a hearing before the Ontario Human Rights Tribunal in *Braithwaite and Illingworth v. Attorney General for Ontario and Chief Coroner of Ontario*,[1] the lawyer for the provincial government made the claim that listening to historical accounts of abuse of insane asylum inmates from the 19th and 20th centuries was "ancient history."[2] At issue was the relevance of past abuses of psychiatric patients to contemporary practices in mental institutions. The hearing was focused on the suspicious deaths of Renata Braithwaite and Robert Illingworth who died while in psychiatric facilities. Their families brought forward a complaint before the Ontario Human Rights Commission in which they, and three interveners,[3] advocated for the province to have an automatic coroner's inquest whenever a patient dies in a psychiatric facility.

The position of the government lawyer is predicated on the erroneous assumption that "ancient history" is so long ago as to be irrelevant to the issues under consideration. Since the history being dealt with here is, in fact, not ancient but concerns history that happened within the life-times of many of our parents and grandparents, it is not nearly as far removed as the "ancient history" moniker would suggest – a term deliberately used to distance us from a past that is much closer than the government is comfortable with – thus the need to push it away into oblivion.[4] This raises the question: Why is history necessary at this or any inquest affecting psychiatric patients? An inquiry into the discriminatory provisions of the *Coroners Act*[5] regarding the deaths of people in psychiatric facilities, if it is to be at all fair, needs to have a discussion of the historical context in which age-old prejudices and abusive conduct towards psychiatric patients is linked with government responsibility. Otherwise, the pattern of unfair treatment that is at issue will be devoid of any serious context as to its past occurrence and continuing perpetuation. There is precedent for an historian advocating for change based on recognition of the links between past injustices and ongoing discrimination as is noted by the highly regarded American historian of medicine, David J. Rothman:

> [H]istorians, like other citizens, may wish to bring their expertise to the support of a cause, to seek to bring justice to a person or to groups that, in their view, have been injured or wronged. In this effort, they serve as advocates and agents of change and their justifications, I believe, should recognize this fact. For myself, serving as expert witness represents a declaration of sympathy for those pressing the case, for the cause they represent, for the equity they wish to achieve, and for the changes they want to protect or realize. Some judges, and perhaps some colleagues as well, may prefer to think of expert witnesses as purely neutral and without personal commitment to the outcome. Such a stance, however, is not only unrealistic but also misguided. Advocacy has its place, and it can be promoted without compromising the craft.[6]

The government's attempt to discredit such testimony also rests on the idea that an historian who advocates a view contrary to their own lacks "relevant expertise," as was stated in their appeal in this case.[7] Yet this position fails to acknowledg that being biased does not mean being unfair. Indeed, for the government to be fair, they would have to acknowledge their own bias in favour of the status quo with no automatic coroner's inquest into psychiatric patients' deaths which is just as biased a view as is any alternative perspective. Similarly, the government needs to acknowledge their own biased, narrow and elitist reading of what they mean by "expert." The government position of who is an expert is based on a 1994 Supreme Court of Canada ruling in *R. v. Mohan* which included "relevance" and "properly qualified expert" as two of four criteria.[8] Relevance is evident in this case based on comparing past abuses with current practices to indicate historical continuity of disregard for a disadvantaged group. A Properly qualified expert needs to take into account the life experiences of witnesses who have lived and worked as a member of the community of people who are the focus of a particular inquiry and who are also engaged in research which directly relates to the people concerned.[9] In this regard, to ignore historical context is to invite a willful ignorance of history even though this context is fundamental to understanding such a contentious issue based in our past as it relates to the present. Such a position reveals an insensitivity which would be shocking were it visited upon another community seeking redress for a particular injustice whose history of being discriminated against is well known and clearly documented. Imagine the uproar if a public official said the history of sexism towards women in hiring practices in a particular field was irrelevant, even if it was well known and well documented. Such a historical context would be highly relevant to the case and would show a pattern of discriminatory behaviour towards an identifiable group throughout a particular period of time until the present, which is essential to know about when arriving at a decision. So too is it relevant in this instance to understand the context of the historical prejudice which pervades the history and ongoing discrimination against psychiatric patients who die in psychiatric hospitals.

The government described the historical testimony at this inquiry as "irrelevant, inflammatory and prejudiced to the question of whether the *Coroners Act* is, today, discriminatory."[10] The government is clearly stating that the understanding of history in this regard is a waste of time, that there is no connection between historical prejudice and contemporary practice. The government's attempt to portray the past in such a way underscores a fear of the past, that history will reveal the province's record of indifference over such a long time on an issue of human rights for some of the province's most marginalized people.

After all, it is not a sign of progress that the Ontario government of the early 21st century is carrying forward a policy that mirrors the provincial government practice of the early 20th century. If a patient died one hundred years ago in a provincial psychiatric hospital, there was no requirement to hold an inquiry of any kind. Yet, this has been a long-standing rights demand of people confined in mental institutions – the Alleged Lunatics' Friends Society advocated for this change in Britain during the mid-1800s.[11] This absence of a mandatory inquest is still in place in Ontario today 150 years later in spite of serious questions being raised about deaths in hospitals. If the government finds this history inflammatory, then it is because history can indeed be inflammatory, especially when it is not addressed, when it is denied, or when its relevance is dismissed as "ancient history." It is especially inflammatory for the people who have lived it, or, in this instance, for the families of people who have died in a psychiatric facility without any inquest into their deaths being held, a long-standing practice in Ontario.

This history, where the deaths of psychiatric patients are not taken seriously enough to warrant an automatic coroner's inquest by the government who are responsible for them, is nevertheless a historical and current fact which has it roots in the long-term prejudice which psychiatric patients have faced and continue to face to this day. Indeed, upon appeal, the court acknowledged that psychiatric patients are, in fact a historically disadvantaged group, though not enough to warrant an automatic coroner's inquest upon death.[12] When considering the deaths of psychiatric patients in asylums one hundred years ago, one would be hard pressed to find how due regard for these individuals is more respected today than in those times which the government lawyer referred to as "ancient history." Whatever else has changed for the better in regard to patients' rights, this part of government policy has not changed and its perpetuation is based in historical discrimination that is still with us today.

Renata Braithwaite and Robert Illingworth have had to struggle for years to try to find answers about the deaths of their mother, Melba, and brother, Thomas, respectively. The struggle they have had to endure, and the obscurity to which the deaths of Melba Braithwaite and Thomas Illingworth would have otherwise been consigned but for their family's fight for answers, did not come out of thin air. It has its roots in the very history of prejudice and dismissal of the views of psychiatric patients which are documented in the pages of the past and in the position of the province of Ontario in regard to long overdue changes to the *Coroners Act*. Rather than continuing this history of discrimination it is time to change history by advocating that an inquiry be held into the deaths of people who die in psychiatric facilities in Ontario beginning with Melba Braithwaite and Thomas Illingworth. Let's make sure that what happened to them and so many other psychiatric patients who died under treatment are not dismissed one day as nothing more than "ancient history."

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1 (2006), 56 C.H.R.R. 171 (H.R.T.O.).

2 The hearing date being referred to here was on January 11, 2006. The Tribunal, presided over by Justice Peter Cory, decided in favour of inquests in regard to the two deaths under consideration. The government successfully appealed this ruling at Divisional Court but that decision is being appealed to the Court of Appeal.

3 The three interveners were the Empowerment Council, Mental Health Legal Committee and Psychiatric Patient Advocate Office.

4 This leaves aside the notion that the *genuine* ancient past, i.e., the period before the 6th century AD, is irrelevant which, of course, is absurd. To take but one example: some of the world's most enduring religions, after all, are based in "ancient history" – quite literally – and are very much still relevant today for large numbers of people across the globe and around the corner.

5 R.S.O. 1990, c. C.37.

6 David J. Rothman, "Serving Clio and Client: The Historian as Expert Witness", *Bulletin of the History of Medicine* 77 (Winter, 2003), p. 44.

7 *Ontario (A.G.) v. Ontario (Human Rights Commission)*, [2007] O.J. No. 4978 (Div. Ct.) (Factum of the Appellants, Vol 1, p. 19) [*Braithwaite and Illingworth*]. Unfortunately for the government, they made serious mistakes in claiming that I have not investigated psychiatric history beyond 1940 which is completely false as my curriculum vitae in their possession proves; two articles published by the time of the hearing include research on the second half of the 20th century, up to the 1990s (and a third article dealing with this more recent past has been published since then). I also give talks on recent, as well as distant, aspects of psychiatric history as the government lawyers could see from the c.v. in their possession. The government also claimed that my work does not include the perspectives of doctors which again is patently false, misleading and dishonest. The purpose of my work is clearly to show the points of

view of patients first and foremost. Yet, a reader has only to quickly glance at the index of my book (as one example among others), to see how completely inaccurate the government's claim is, as there are dozens of references to the views of medical superintendents at the facility in question: Geoffrey Reaume, *Remembrance of Patients Past: Patient Life at the Toronto Hospital for the Insane, 1870-1940* (Toronto: Oxford University Press Canada, 2000). The dishonesty of the government's claims reveals their own standards of "fairness" and "bias" in this particular case, in which distortion of an author's work to advance their own agenda is more important than serious engagement with the past on the issue in question.

[8] *R. v Mohan*, [1994] 2 S.C.R. 9, page 1. The factors which provide for an expert in this decision are: relevance; necessity in assisting the trier of fact; absence of any exclusionary rule; a properly qualified expert. In addition to the two cited factors noted in this article, the other two factors also apply here – assisting the trier of fact is based on the contextual evidence a historian can provide; and absence of an exclusionary rule applies based on the knowledge and experience of this topic matter under consideration as defined by the Supreme Court, cited above: "The evidence must be given by a witness who is shown to have acquired special or peculiar knowledge through study or experience in respect of the matters on which he or she undertakes to testify." Given the elitist notions of who can claim expertise, with those of us with doctorates more likely to be recognized than those without, it is essential to recognize the expertise of the lived experiences of people from the community under investigation which all of us learn from, are indebted to and need to respect, regardless of the formal education of the individuals in question.

[9] Notions of "expertise", who can claim this mantle, who is excluded and why, are well known debates in the humanities and social sciences in recent decades so it is a bit of a surprise that the government would use this term in such a unprofessional and uninformed manner without reference to these debates. In disability studies in recent years, this is a widely debated issue in which people with disabilities have come to be recognized as experts about their own lives and history. See for example: Colin Barnes, "What a Difference a Decade Makes: Reflections on doing 'emancipatory' disability research", *Disability & Society* 18:1 (2003): 3-17; Brenda Jo Brueggemann, "An Enabling Pedagogy" in *Disability Studies: Enabling the Humanities* eds. Sharon I. Snyder, Brenda Jo Brueggemann, Rosemarie Garland-Thomson (New York: The Modern Language Association of America, 2002): 317-336; Paul K. Longmore. and Lauri Umansky, "Disability History: From the Margins to the Mainstream", in Paul Longmore and Lauri Umansky, *The New Disability History: American Perspectives* (New York: New York University Press, 2001): 1-29; Marie Knox, Magdalena Mok, Trevor S. Parmenter, "Working with the Experts: collaborative research with people with an intellectual disability", *Disability and Society* 15:1 (January 2000): 49-61; Dan Goodley and Michele Moore, "Doing Disability Research: activist lives and the academy" *Disability and Society* 15:6 (October, 2000): 861-882; Rob Kitchin, "The Researched Opinions on the Researched: disabled people and disability research", *Disability and Society* 15:1 (2000): 25-47; Peter Beresford, and Jan Wallcraft, "Psychiatric System Survivors and Emancipatory Research: Issues, overlaps and differences" in *Doing Disability Research* eds. Colin Barnes and Geof Mercer (Leeds: The Disability Press, 1997): 67-87; Colin Barnes, "Disability and the Myth of the Independent Researcher", Disability and Society 11:1 (1996): 107-110.

[10] *Braithwaite and Illingworth* (Factum of the Appellants, Vol 1, p. 20).

[11] Nicholas Hervey, "Advocacy or Folly: The Alleged Lunatics' Friends Society, 1845-63," *Medical History* 30:3 (July, 1986), p. 258, note 76.

[12] *Braithwaite and Illingworth.*

OAK RIDGE: PAST, PRESENT AND FUTURE

How the History and Redevelopment of Ontario's Maximum-Security Psychiatric Hospital Parallels Societal Attitudes and Treatment of Forensic Patients

Dan Parle[*] and Sharon Zwicker[**]

The year is 1933. All of North America is locked in the grip of an unprecedented depression that has torn the social fabric of society. Governments at all levels are turning to public works projects to provide some kind of employment for the legions of young men who are on the move.

On a cold February day, a train left Guelph with the first group of patients headed to Penetanguishene for a transfer to the "New Building" which had just been constructed on the grounds of what was then known as the Penetanguishene Asylum for the Insane. The transferred patients, all men, had been held in the Guelph Reformatory.

All had been found Not Guilty By Reason of Insanity or Unfit to Stand Trial after being charged with a variety of crimes, frequently murder. The Ontario government had finally recognized that these men were not technically the responsibility of the Ministry of Corrections because mental illness had made them "incapable of understanding the nature and quality of the act or omission or of knowing it was wrong."[1]

The new building, which would eventually come to be known as Oak Ridge, was and always has been operated by the Ministry of Health and Long-Term Care. The first half of the building that was constructed in 1933 was primarily designed to be custodial. Although technically a hospital, it lacked even a visiting room and recreation area. Most of the staff were attendants trained on the job. Clinical staff was limited to two or three nurses and doctors.

On the arrival date for the first patients in February, hospital officials, anticipating trouble from a nervous population, asked the Ontario Provincial Police to barricade the roads from the train station to the new building located on a hill above the mouth of Penetanguishene Harbour. A few young boys threw snowballs at the disembarking patients, who seemed anxious to get out of the biting wind, but that was the limit of protest.[2] The facility has had a remarkably supportive relationship with the Town of Penetanguishene ever since.

The construction of Oak Ridge and the separation of offenders found "Not Guilty by Reason of Insanity"[3] from the prison population can be viewed as one of the final responses to a reform movement sparked and led by American crusader Dorothea Dix starting around 1841. Dix was appalled to find, while teaching a Sunday school class at the East Cambridge Jail in Massachusetts, that many mentally ill people were restrained and neglected there. Many had never been charged with a crime. When Dix expressed shock at their condition, she was told "the insane do not feel heat or cold."[4]

Dix became the leader of an effective campaign to decriminalize the mentally ill that spilled across the border and eventually led to the establishment of the psychiatric hospital systems in many states and provinces. The Oak Ridge population has always been difficult to reconcile with this movement: they were part of a small, rarified group that was both mentally ill *and* had committed a serious crime.

The first half of Oak Ridge opened in an era prior to the development of many therapies common today. The therapeutic approach at the time, such as it was, consisted of the waning concept of "Moral Treatment" – three square meals a day, good hygiene and work if the patient was capable.

Patients who were institutionalized anywhere in the 1930s entered a world where the mentally ill had few rights. All patients throughout the psychiatric system were generally viewed as incompetent and staff, often poorly-trained, held full sway over their charges. As long as the staff and administration of an institution were benevolent, they did their best for their patients in an era with few effective treatments for mental illness and few resources devoted to care. Certainly, the absolute power that caregivers had over the mentally ill led to some documented abuses and set the stage for an even stronger struggle to protect the rights of the mentally ill in the decades to come.

Oak Ridge patients at the time were often viewed by the general public as malingerers -- murderers who had escaped the hangman's noose by feigning mental illness.[5] Successful insanity acquitees were not expected to return to society. Few gave much thought to their long-term care and treatment.

The introduction of many active treatments in the 1940s and 1950s brought significant changes to psychiatric care at Oak Ridge and throughout the world. Electroconvulsive therapy (ECT), early tranquilizers and antipsychotic medications were all introduced in Ontario during this period. These treatments were intrusive but also had demonstrated some effectiveness. Many patients were stabilized and showed improvement.[6]

Eventually, concerns about these treatments led many advocates to call for safeguards to ensure the mentally ill gave informed consent to any treatment or, if they were incompetent, a substitute consent giver did. A series of changes were made to the *Mental Health Act*[7] over the next few decades to establish and strengthen these rights.

By 1953, the first four wards of Oak Ridge were overcrowded beyond their original capacity of 152 and few patients ever left. By 1955, the Province had constructed and opened an additional four wards to bring capacity to 304 patients. The new side had a recreation facility, but still no visiting complex and the facility still lacked many features associated with hospitals of the era.

1960 to 1970 was a tumultuous decade for society in general and for health care in particular. Oak Ridge began to hire many more clinicians who were not doctors and nurses. This influx of social workers, psychologists, recreationists, occupational therapists and other qualified professionals would eventually have a strongly positive impact on therapy at Oak Ridge. As part of this "professionalization" of the Oak Ridge staff, a few years later the facility would begin a lengthy program that financially supported willing attendant staff to attend school and become Registered Nursing Assistants.

Dr. Barry Boyd, a psychiatrist who was superintendent of the facility from 1960 to 1978, used to be fond of saying in jest: "Half the patients in Oak Ridge aren't dangerous. If I knew which half it was, I would let them go!"

Despite Dr. Boyd's candor about his profession's ability to assess risk in forensic patients, he was instrumental in helping to establish the Lieutenant Governor's Board of Review, an advisory group which began to review every patient's status yearly and recommend some for release to lesser secure facilities.[8] The hospital's Research Department, established in 1975, eventually became internationally known in part for its work developing actuarial tools to help clinicians assess recidivism risk in patients.

From 1965 to 1978, half of Oak Ridge was devoted to the Social Therapy Unit, an intense therapeutic community designed to treat men with the diagnosis now called severe antisocial personality disorder, but then known as "sociopathy" or "psychopathy" (although men with other diagnoses, including schizophrenia, were also treated in this program). Where to house and how to treat this group of severely antisocial men is an ongoing discussion in forensic psychiatry often summed up in short form as: mad, bad or both? In the modern era, men with this diagnosis who are found by the courts to have committed a criminal offense are usually found guilty and sent to the correctional system.

1978 brought substantial changes to the *Mental Health Act*, which intended to protect the rights of all psychiatric patients, including the right to hire counsel and appear before a Review Board to challenge an involuntary committal and the right to access all documents and appeal. While some of these things were already common practice, the new sections were intended to enshrine these rights in law. Due to heated opposition from psychiatrists and the medical profession, these two sections were not proclaimed until 1984.[9]

The Psychiatric Patient Advocate Office was established to protect and explain some of these new rights that had been extended to psychiatric patients. By 1983, 11 Advocates had been hired, but they met with some resistance. As the Director of the Oak Ridge Forensic Unit told the Toronto Globe and Mail at the time:

> The Advocate is a frustration and an irritant. I felt that I was my patient's best advocate, that I was acting in his best interests and now all of a sudden this guy can come and look over my shoulder with rather sweeping powers and ask for explanations…[10]

In the years since, mental health professionals at Oak Ridge and across the province have adjusted to the improved rights protection for the mentally ill and the presence of professional Advocates.

The population was gradually reduced from a high of over 300 to as low as 120 and currently is 160 men. The empty rooms were converted to clinical offices, examining rooms, libraries, kitchens and other therapeutic uses. The most common diagnosis for the current population is schizophrenia. For Oak Ridge patients, it is often paranoid schizophrenia and refractory (meaning hard to treat or treatment resistant). Today, Oak Ridge has skilled interdisciplinary clinical teams that offer a wide variety of programming for patients who choose to take it.

Despite improvements, there is general agreement that the current Oak Ridge physical plant is antiquated, prison-like and unable to meet national standards of care. Dr. Brian Jones, a psychologist who is the current Chief of the Forensic Division that includes Oak Ridge, has described the patients there as "some of the most disadvantaged in the province."

After years of planning and study, the Minister of Health and Long-Term Care, George Smitherman, announced in late 2007 that the Oak Ridge physical plant would be replaced. Ground breaking is scheduled for 2010 with occupation in 2013. Detailed plans and design for the new structure have not yet been unveiled, but we do know that it will not look anything like the current Oak Ridge. The new Oak Ridge will be bright and meet the quality of life needs of its patient population. Both society and the patients will be protected. It will be a humane environment offering the best possible treatment for a difficult population.

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1 *Criminal Code*, R.S., 1985, c. C-46, s.16 (1).
2 Nielsen, Robert F. (2006). *Total Encounters: The Life and Times of the Mental Health Centre Penetanguishene* (2nd Ed., page 64). Penetanguishene: Mental Health Centre Volunteer Association
3 "Not Guilty By Reason of Insanity" was later replaced by "Not Criminally Responsible due to Mental Disorder" In the *Criminal Code*. This language conveys the finding that mental illness has left the perpetrator less culpable than those of sound mind.
4 Women's Intellectual Contributions to the Study of Mind and Society, opening page, retrieved February 14, 2008 from http://www.webster.edu/~woolflm/dorotheadix.html.
5 Canada did not formally abolish the death penalty until 1976 but it stopped executing prisoners by the early 1960s.
6 ECT has received a lot of criticism as a therapy, but has continued to be used in Ontario. Changes were made to reduce side effects and intrusiveness. The scientific literature supports its effectiveness as a treatment for depression and schizophrenia. However, at least one treatment from this era, psychosurgery (usually in the form of frontal lobotomy), was specifically outlawed in the province in 1978 due to a public outcry over this operation's crude technique, unpredictable results and questionable efficacy. Psychosurgery had already been in decline for over a decade.
7 R.S.O. 1990, c. M.7.
8 In 1992, this board was replaced with the Ontario Criminal Code Board of Review and later renamed the Ontario Review Board. It has the power to set security levels, conditions and release for forensic patients.
9 These sections were later repealed in further amendments to the *Mental Health Act* in 1992 but these rights remain entrenched.
10 Simmons, Harvey G. (1990). *Unbalanced: Mental Health Policy in Ontario 1930 – 1989*. Toronto: Wall and Thomson, page 234.

BUILDING ON HISTORY:
THE CENTRE FOR ADDICTION AND MENTAL HEALTH IN THE 21ST CENTURY

David S. Goldbloom*

The History

The story of the Centre for Addiction and Mental Health (CAMH) begins on January 26, 1850, when the Provincial Lunatic Asylum, as it was then called, first opened its doors. It was the largest public non-military building in Canada, with central heating, hot and cold running water and indoor washrooms[1] - and it was Ontario's first asylum.

The stage for its construction was set in 1839, with the passing of *An act for the building of an asylum for the care and treatment of the insane and lunatics of Upper Canada*. However, 11 years elapsed before it was actually built due to lack of funds and jurisdictional disputes. This set the stage for the future pace of mental health reform for the next two centuries! From 1841 to 1850, there had been a temporary asylum established in the old York Gaol on King Street.[2] Then, in May 1845, the British Ordnance Department granted a 50-acre rectangle of land in the northern part of the Military Reserve.

The name Provincial Lunatic Asylum was perfectly acceptable in 1850. Originally, the term lunatic, defined as "someone affected by intermittent insanity attributed to changes in the moon," was an effort to place some meaning and origin on human suffering that was otherwise inexplicable. An asylum, now a largely maligned term in health care that evokes negative images, referred in 1642 to "a secure place of refuge or shelter" and in 1776 to "a benevolent institution affording shelter and support to some class of the afflicted, the unfortunate or destitute."[3]

John George Howard, a leading architect in Upper Canada at the time, was selected to build the asylum. He travelled to both the United States and Europe to study other models of psychiatric hospitals. He quickly learned that for asylum architecture, form was to follow function. He also discovered, as do many modern architects who work on government-funded projects, that the ideal is often constrained by budget, government policies and political considerations.

"Moral treatment" was the most advanced and humane treatment at the time. It recommended that every patient should be treated kindly, that there should be good surveillance at all times and that health came from being in the ideal environment and interacting with nature. Patients were classified by symptoms and were only to mix with those of the same diagnostic class and gender, in a soothing and dignified environment. Patients who were classified as curable were allowed more time with staff and meaningful work within the asylum. The assumption was that kindness was curative. Modern treatments have not eliminated the need for that fundamental human intervention.

In keeping with these tenets, Thomas Kirkbride, the leading mid-19th century American expert on asylum construction, set out certain parameters. He said that an asylum should be small, housing no more than 250 patients, and that the building should facilitate the proper classification of patients. We humans are relentless classifiers; man's first response to ignorance is often taxonomy. Lighting, heating, ventilation, and that critical element of all modern business success - location, location, location - were also deemed to be critical. The asylum needed to be set in the countryside, in order to provide a relaxed and tranquil environment.

Howard built the asylum in keeping with the Kirkbride guidelines. For example, he built an extensive system of staircases that separated the different classes of patients. And, as the integration of therapeutic work was a very essential part of this treatment, the grounds and farmland were important features of the Toronto asylum. The land, which is now situated in a downtown thriving neighbourhood, was located just outside the city limits, three miles west of the noise, the smoke and the smells of Toronto. However, the building was larger than Kirkbride recommended, as Howard had been instructed by government officials to build a 500-bed asylum.

For the next 158 years, an asylum for the mentally ill stood on this site while the city of Toronto grew to envelop its perimeter. Roughly a century after the asylum first opened, three new facilities opened elsewhere in Toronto. At College and Spadina, the Clarke Institute of Psychiatry served as the centre for academic psychiatry at the University of Toronto, combining a modest hospital capacity with an extensive research and teaching profile. The Addiction Research Foundation, immediately next door to the Clarke physically but with no clinical or academic connection, was established to advance understanding and treatment of substance abuse and developed an international reputation. In North Toronto, Canada's first publicly funded hospital for addictions opened as the Donwood Institute. Over the next half-century, each of these institutions developed their own unique cultures, identities and achievements.

In 1998, the Health Services Restructuring Commission traveled through Ontario and reworked the hospital landscape. Among its creations was the Centre for Addiction and Mental Health, bringing together these four distinct institutions. Why?

People with mental illnesses are at high risk for development of addictions, and the same is true in the opposite direction. However, traditionally throughout Western society the treatment of addictions has been separate from that of mental illnesses, serving the needs and interests of professionals but not those of people affected by these problems.

CAMH was created to correct that separation, to acknowledge the reality that people often experience these two sets of problems together. It was also created to integrate world-class research with both front-line clinical care and the training of the next generation of healthcare professionals; this reflects a belief that the best care occurs when informed by the latest knowledge and challenged by our brightest students.

As a result of this merger, CAMH became Canada's largest and leading academic health sciences centre devoted exclusively to mental illness and addiction and the flagship hospital in this area for the University of Toronto. In addition, by 1999, the World Health Organization declared CAMH one of four centres of excellence worldwide – the others being Harvard University, the Institute of Psychiatry in London, England, and the National Institute of Mental Health and Neuroscience in Bangalore, India. In a new way, CAMH was thrust onto the world stage – and in the last decade, it has never left it.

Fortunately, CAMH owns the 27 acres of downtown land that has been the historic site of an asylum for the mentally ill for more than 150 years. The land is now a large rectangle, surrounded by a residential neighbourhood on all four sides. This extraordinary real estate provides the opportunity to realize the mission of CAMH in the heart of downtown Toronto:

- To integrate mental health and addictions care in a setting that reduces stigma and isolation and promotes hope, health, and recovery;
- To become part of a thriving residential neighbourhood and normalize the environment so that people with mental illnesses and addictions no longer feel marginalized; and
- To create state-of-the-art research and teaching facilities that will act as a magnet internationally and will generate skills and knowledge of benefit worldwide.

The Design

The first set of new buildings opened in April 2008. They represent the first phase of an ambitious building project that will transform the west end of downtown Toronto. Several years ago, over 60 architectural firms competed for this rare design opportunity. Most hospitals, particularly in major urban centres, have to build vertically on a small footprint of land. The unique opportunity to transform a 27-acre footprint in the heart of the city inspired architects to think beyond the typical hospital design.

The winning team, a consortium of three internationally renowned Toronto firms (Kuwubara, Payne, McKenna, Blumberg; Montgomery Sisam; and Kearns Mancini), developed the theme of "an urban village." Rather than maintaining a single 27-acre city block with all roads ending at its perimeters, roads will now bisect the property, creating normally sized city blocks and human traffic that fit into the community and provide greater safety. Rather than creating single large buildings, there will be a network of smaller buildings spread over the 27 acres, designed to integrate into the surrounding residential neighbourhood, with streets and public parks interspersed throughout.

Our patients, families, and staff told the architects about the importance of sunlight, fresh air and a home-like setting as being important determinants of a key component of recovery: hope.

As a research centre, we believe strongly in scientific evidence. There is already a large and strong evidence base for healthcare design and architecture, as reflected in nearly 700 studies of how the architecture of hospitals affects health.[4]

In addition, critical components of the design include a setting that is respectful and dignified for patients. For many centuries, people with mental illnesses and addictions have been housed and treated in environments that would never be tolerated for people with physical illnesses. In the 21st century, this can no longer continue.

The redevelopment will encompass 2.6 million square feet of space spread over the 27-acre property. CAMH actually will require only 1.3 million square feet for its activities. The remainder will be made available via long-term land lease for development by the private or public sector. We will never sell the land but we do wish to see it developed for several reasons:

- A continuing source of revenue;
- A normalization of the environment; and
- A service to the surrounding neighbourhood.

The CAMH buildings themselves will incorporate our extensive inpatient facilities (480 beds), outpatient services, educational facilities, research laboratories, and offices related to policy, health promotion and prevention. They are being designed to incorporate flexibility that will allow us to accommodate to future needs and realities.

The clinical areas reflect the input of countless patients, families and staff as well as the experience of our architects in designing and visiting healthcare facilities internationally. Themes of dignity, respect and comfort are inherent in the design, as are activity, self-sufficiency, progress and hope. Given the widespread nature of mental illnesses and addictions, we must build centres of care that pass the personal standard of judgement – "Would I want my brother to be cared for here? My daughter?"

The educational areas will not only ensure that knowledge is shared – among colleagues, to the next generation of health professionals, to patients, families and the general public – but also leverage technology. The classroom walls will be knocked down as we connect in real time with students around the globe and learn from teachers internationally.

The Centre for Discovery and Knowledge Exchange, housing our research operations, will provide our distinguished scientists and promising junior scholars with ample laboratory space and cutting-edge technology to make important and much-needed scientific breakthroughs.

We have a set of principles related to the non-CAMH buildings that will be erected, to ensure they are consistent with the values of CAMH as a health care organization. Facilities such as grocery stores, banks, coffee shops, art galleries, and supportive housing are among the envisioned tenants. We will promote employment opportunities for people with mental illnesses or addictions, as we believe strongly that work, self-sufficiency, and financial reward are important determinants of self-worth and self-esteem.

We have created three public parks that will be deeded in perpetuity to the city of Toronto. In addition, there will be healing gardens created for all inpatient units and access to fresh air and light.

Nowhere else in the world has a centre of our scope, size and significance been built in the heart of a major metropolitan urban environment. In this regard, the eyes of the world are upon us. Expectations are high and we must succeed. Our goal is for CAMH to be a beacon of hope for people in the 21st century as they, their friends, and their families grapple with the problems of mental illness and substance abuse – problems that affect all our families.

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MENTAL ILLNESS AWARENESS WEEK: LEADERSHIP, HOPE, RECOVERY

Martin Sampson*

Health is a precious gift, often undervalued by those who enjoy it, and desperately wished for by those who do not. In many cases, people who live with poor health have difficulty focusing on other aspects of their lives because they are preoccupied with trying to get better. For someone who experiences an illness, the journey back to health can be a complicated process because good health is so much more than physical well-being and the simple absence of disease. Health is a complex human condition, the result of harmony between a person's physical, emotional and mental states. Each state has a direct and profound impact on the others. Too often, though, the focus is on physical well-being. But the reality is, if any element of a person's well being is out of balance, poor health can result. Simply put, there is no health without mental health.

That is why for millions of Canadians who live with depression, bipolar disorder, schizophrenia or other mental illnesses, leading a happy, healthy and fulfilling life can be challenging. Often, mental illnesses can have a profound and devastating impact not only on an individual's mind, but by extension on their lives in general, and on the lives of the people who are close to them.

"Conservatively, we estimate that 7.5 million Canadians suffer from depression, anxiety, substance abuse or another mental disorder," says Phil Upshall, National Executive Director of the Mood Disorders Society of Canada, and chair of Mental Illness Awareness Week. "That's one in four. When you extend that number to the impact on family members, friends and co-workers, virtually no Canadian is excluded from the effects of mental disorders."

He says, despite the prevalence of mental illness, the stigma is often so strong that it prevents an individual from seeking treatment and help.

"If a Canadian is diagnosed with a physical illness, a problem with the biochemistry of one of their organs or a cancer of their cells for example, their community usually comes together, surrounds them, cares for them, and helps them heal," says Upshall. "But if a Canadian experiences a problem with the biochemistry of their brain, and that problem manifests itself in the form of a mental illness, that individual is often – through societal prejudice, discrimination, and ignorance – isolated and left alone by family, the medical community, colleagues and friends to work their way through what can be a lonely and terrifying experience."

Recovery is a complicated process that in so many ways depends on positive self-esteem which comes from a connectedness to loved ones and to the community. The recovery process for any disease can be difficult. But for those who live with a mental illness, the challenges encountered during the healing process are too often exacerbated by the discrimination, ignorance and fear which is wrongfully associated with these diseases. In many cases, the discrimination and shame attached to the disease can be more painful and more debilitating than the disease itself.

It is in order to combat this ignorance, discrimination, and prejudice, as well as to advocate at the national level so that more attention is paid to mental illnesses by all departments of the federal government, the Canadian Alliance on Mental Illness and Mental Health (CAMIMH), a coalition of 19 national NGOs, service providers and professional associations, coordinates and delivers Mental Illness Awareness Week (MIAW). For more information about CAMIMH, please visit www.camimh.ca.

MIAW is an annual national public education campaign that takes place the first full week of October and is designed to raise awareness among Canadians about the significant social and economic impact mental illnesses have on our society. Since its creation, MIAW has grown exponentially from a small yet powerful grassroots initiative into a truly national public awareness campaign. Campaign elements include a public education initiative, a national social marketing campaign, the annual Champions of Mental Health Awards, and education initiatives aimed at senior government and corporate leaders.

An integral component of MIAW is the Face Mental Illness (*Faces*) campaign which features Canadians who are living successfully with a mental illness. They share their stories through a nationally distributed poster and bookmark series, on the website, and in all print and broadcast public service announcements in order to raise awareness about and lower the stigma attached to mental illnesses. Since the inception of the Face Mental Illness campaign in 2003, 40 courageous Canadians have shared their stories. You can read them at www.miaw-ssmm.ca.

Another important component of MIAW is the Champions of Mental Health Awards. The Awards recognize the efforts of individuals and groups who have made an outstanding contribution to advancing the mental health agenda in Canada. Over its five year history, the Awards have brought together more than 1,500 members of the MIAW network: parliamentarians, senior bureaucrats, business leaders, sponsors and stakeholders who have been able to achieve much more together than they would have been able to achieve independently. Since the inception of the Awards in 2003, more than 29 individuals and groups have been honoured for their efforts. The recipients are a distinguished group of Canadians who include doctors, parliamentarians, business leaders, researchers, writers, leaders from the First Nations, Inuit and Métis communities, and journalists. You can also read their stories at www.miaw-ssmm.ca.

Through MIAW, hundreds of stories that would otherwise never have been shared have been told, thousands of stakeholders have been engaged, hundreds of thousands of dollars have been raised, and millions of Canadians have been reached.

"The initiatives that we have undertaken during MIAW over the course of the last five years have made a real difference," says Upshall. "But there is a lot more we can do. While we are happy with our achievements, we are firmly focused on the future. This is an issue whose time has come, and we will not stop until the stigma associated with mental illnesses is erased and until appropriate access to health care professionals, hospitals and community supports, including housing, is provided to those who need it."

In 2007, with the help of stakeholders, sponsors, corporate leaders and with the courage of the MIAW *Faces* of mental illness, MIAW messages of hope, compassion, leadership and recovery reached more than 12,000,000 Canadians. The campaign is poised to grow even larger in 2008 and beyond. Through these successes, the MIAW campaign is making a substantial contribution to defeating the discrimination and prejudice that is too often associated with mental illnesses.

As a society, we need to change the way we think about mental illnesses. We must be more aware about the realities of this group of diseases. We must eradicate the discrimination attached to them. We must be compassionate. Mental Illness Awareness Week is one initiative that endeavours to make the required change happen, and although much has been accomplished, the reality is, much work remains.

To find out how you can help or for more information about MIAW, please visit www.miaw-ssmm.ca.

* Martin Sampson is a communications professional who has worked in the mental health advocacy field in Canada for the last three years. He is the project manager for Mental Illness Awareness Week.

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FROM LUNATICS TO CITIZENS

Nérée St-Amand* and Eugène LeBlanc**

The following constitutes an analysis of labels used over the past two centuries for people who were diagnosed and treated for mental illness.

This text is part of research conducted by Eugène LeBlanc and Nérée St-Amand about the history of mental health services in New Brunswick and was published in April 2008 under the title *Dare to Imagine: From Lunatics to Citizens.*[1]

The manner in which we label: names say it all

Is labelling people a therapeutic endeavour or a political gesture? The two authors who studied the growth of institutional and community psychiatry in New Brunswick suggest that there is a political dimension of labelling people suffering from so-called mental problems. Furthermore, they demonstrate that the reactions of individuals and groups affected with mental health problems has been marked by debates and controversies. Their analysis of diagnosis suggests that history can be divided into four different stages.

1824-1945: Names range from lunatic, imbecile, crazy and idiot to patient

Until 1945, those committed into the psychiatric institution were generally labelled as lunatics, crazy, idiots, and imbeciles. Little effort seems to have been made to question the methods of labelling people or to understand the social reasons for such labels..

With the arrival of modern psychiatry and the advent of the Diagnostic and Statistical Manual (DSM) of Mental Disorders, crazy people became patients of a system that became increasingly medical. This happened around 1945 when electro-shock therapy and X-rays were introduced at the New Brunswick's Provincial Hospital in St. John, and compounded by the recognition of psychiatry as a science in the western world. Coincidentally, psychiatry became even more legitimate and began expanding onto the scene at the same time as World War II. It should be noted that the war caused much psychological and psychiatric trauma to returning soldiers and their families.

1945-1975: From patient to mental patient, consumer and client

Established in the 1960s, the consumer movement impacted psychiatry in the sense that the psychiatrized started calling themselves consumers/clients rather than perceiving themselves as mere patients. However, being qualified as a consumer does not necessarily mean engaging to create change or awareness of the powers at play. It seems that many groups in New Brunswick still see themselves as consumers and remain to this day in a passive state. The Canadian Mental Health Association continues to use this term;[2] thus, it demonstrates its attachment to a history and a way of looking at people that are simply outdated!

1975-1987: From consumer, mental patient, client to psychiatrized, ex-patient, survivor

The survivors movement, coming from the United States in the 1980s, had followers in New Brunswick, notably thanks to the Our Voice/Notre Voix publication. Terms such as survivor and ex-patient convey a political analysis, a critical distance, and a victory on the part of people who have resisted a compressing and domineering psychiatric system. people like Stephen Stiles, Robert MacKay, Roger Melanson, Katherine Tapley and Eugène LeBlanc are important representatives of the movement, and have contributed to the shake up of an abusive psychiatry. Their writings are essential in unravelling the contradictions of institutional psychiatry. A few francophone professionals such as Claude Snow, Annette Després, Ronald Maltais and Nérée St-Amand have also been allies to the cause. However, anti-psychiatry professionals and survivors do not carry the political influence of institutional psychiatry; the latter still has an important stranglehold on a large segment of the marginalized population.

1987-Today: From psychiatrized, ex-patient, survivor to advocate, person, citizen

We are currently witnessing throughout the Western world an increasing political awareness by those who have gone through various experiences with psychiatry, of which they have been and continue to be victims. Thanks to this awakening, these people have become activists and suggest that psychiatry is an integral part of professional and institutional oppression; moreover, some of these victims are ready to use more radical models to put an abusive psychiatry in its place.

On the other hand, a significant number of people who remain subjected to a system are submissively and faithfully accepting what is suggested to them by professionals. As a result, we are faced with two different and opposing views; one suggests acceptance and cooperation while the other is based on resistance and refusal.

For significant change to occur, *survivors* need to become committed *citizens* and play a greater role in the professional and political process. History of institutional and community psychiatry has demonstrated its resistance to change. not much alteration will occur to a medical and institutional system, unless there are intense pressures being exerted or if a large scale scandal takes place.

Despite all the lobbying and commissions of inquiries, professionals, psychiatric hospitals and the Canadian Mental Health Association, still call people *patients*, *clients* and *consumers*. Professionals still treat them as *cases*, or perhaps better said, *consumers*. The general public still continues to believe certain myths about people who are considered to be *mentally ill* (dangerous, need isolation, infectious, etc…). A new paradigm must be put into place so that we can avoid a repetition of past experiences into the 21st century.

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1 The book is available in either English or French from the editor, Our Voice / Notre Voix, P.O. Box 29004, Moncton or ovnvletters@nb.aibn.com.

2 St-Amand 2004: 19-23.

ERASING THE STIGMA

Carol Goar[*]

For more than 25 years, psychiatric survivors have fought with courage and imagination for the simple right to be seen as whole human beings. But their story is one of modest progress, punctuated by crushing setbacks.

As a journalist who has written a few paragraphs of that story, I cringe whenever I see an individual with a mental disorder portrayed in the media as a violent criminal, a pitiable victim, an aggressive vagrant or an imbecile. I know how much damage these stereotypes do. I can imagine how hurtful they must be to people who manage their symptoms as well as humanly possible and make an enormous contribution to society.

Some writers and broadcasters do make a determined effort to erase the stigma of mental illness. But too many carelessly toss off phrases that spread misconceptions and foster unwarranted fears.

It is not, as many psychiatric survivors believe, because journalists are blind, callous or malicious. Most of my colleagues – like most Canadians – have been touched by mental illness. They've watched someone they love battle depression, a bipolar disorder or a destructive addiction to alcohol or drugs. Many have done it themselves.

The problem is, they don't see this as news. They don't know how to fit the struggles and triumphs of people with psychiatric disorders into the conventions of journalism. They aren't even sure it's their role.

The usual result is misleading or non-existent coverage. The media either exaggerate the symptoms of mental illness or ignore the subject entirely.

Much of the responsibility for this unfortunate state of affairs lies with those of us who report and write news. But some of it lies with the mental health community, which too often waits passively for journalists to come seeking information or lashes out angrily when they get something wrong.

Let's examine the failings of the media first.

Journalists look for stories in all the predictable places: on Parliament Hill, at Queen's Park, at city hall, at schools boards, on the police blotter, in corporate boardrooms, at stock exchanges, on film sets, at conferences or in lecture halls. There are people with mental illness in all these places. But it would take a very enterprising reporter, with an extraordinarily supportive editor, to seek them out, earn their trust, find out how they cope, then tell their stories with depth and sensitivity. Most members of the media would rather stick with what they know.

Newspapers and broadcast outlets tend to be risk-averse. They don't like departing from mainstream news coverage. They are nervous about probing issues that might hurt the people involved, upset readers, or highlight uncomfortable truths. They'd rather steer clear of problems that society isn't eager to confront.

Except for a lucky few who produce documentaries and write in-depth features, journalists live in a world of tight deadlines. Their research is limited by the amount of time they can spend. Their contacts are limited by their familiarity with a subject. The resulting stories are frequently superficial.

There is a strong temptation, in a business where success is measured by ratings and readership, to entertain rather than inform. It requires very little effort to air or publish a syndicated story from Hollywood about a pseudo celebrity. It requires a great deal of work to learn about mental illness, find someone who is willing to speak openly, then put together a story that is accurate, balanced, fair and capable of holding readers' or listeners' attention.

These shortcomings are no source of pride to journalists who care about their craft and want to raise the standards of public debate. But they are a reality that those of us within the business and those on the outside trying to deliver a message need to understand.

Now let's look at where mental health advocates have fallen short of the mark.

There is a tendency among those who care deeply about psychiatric survivors to hope news organizations will eventually figure out they are doing a grave disservice to a significant and vulnerable segment of the population. That is a mistake. Silence leads journalists to believe they're not doing anything wrong. Passivity is never a good strategy when the media are spreading incorrect or incomplete information.

There is an assumption among some mental health advocates that journalists only talk to high-profile public figures. That is simply not true. The reason why recognizable names and faces pop up in the news so often is that they're accessible, they want to speak out and they recognize that, whether they like the media or not, they can't afford to ignore a vital pipeline to the public. If organizations working in the mental health field were more visible and more willing to reach out, they'd have a better chance of shaping the public record.

There is an understandable reluctance in the mental health community to expose people who are living with misunderstood illnesses to potential hurt or ridicule. That is a possibility in any encounter with media. But it needs to be balanced against the drawbacks of silence, which include allowing damaging myths to prevail and creating the impression that psychiatric survivors are incapable of speaking for themselves.

There is a natural, but counterproductive, inclination among mental health advocates who have had a bad experience with a journalist to fire off any angry letters, attack the news outlet responsible for the injustice and cut off further communication. This only makes matters worse. It signals to other reporters that writing about mental illness is a high-risk proposition and gives their bosses a strong incentive to slam on the brakes when the subject comes up.

There is a lack of understanding in the mental health community about what constitutes news. It is not enough that millions of people live with psychiatric disorders. It is not enough that these illnesses have been in the shadows for generations. It is not enough that there is a serious shortage of supportive housing, community services and research in this field. Journalists need events. They need people who are willing to share their stories. They need public figures to act as champions for the cause.

There is a belief among mental health advocates that journalists are – or ought to be – conversant with the language they use and ready to adopt it. This is a mistake on two counts. First, most members of the media have no idea what a term such a "consumer survivor" means. Even if they did, they wouldn't repeat it on air or in print because people wouldn't know what they were talking about. It is fair to ask the media to avoid derogatory phrases. It is not fair to ask them to use euphemisms that are unclear or confusing.

Finally, there is a scarcity of positive role models. A handful of brave individuals have disclosed that they live with mental illness. The "Transforming Lives" campaign, launched by the Centre of Addiction and Mental Health, has helped to break the silence that has held back people with psychiatric disorders. But there needs to be more trailblazers. It needs to become normal to say "I have depression" or "I take medication for post-traumatic stress and I'm not ashamed to talk about it."

Clearly, there is a lot of room for improvement. It would be unrealistic to expect a complete alignment of interests. Psychiatric survivors would prefer solely favourable coverage. Journalists don't offer uncritical publicity to anyone. But there are points of convergence.

An adverse event, be it a journalistic mistake or an unfortunate public occurrence, provides an opportunity for public education. Rather than dwelling on what went wrong or berating the culprit, the smart response is to get the real facts out and put a human face on those who are often typecast by their symptoms.

There is no need to wait for such openings. Journalists attend public events, go to lectures and participate in panel discussions. There are some excellent speakers in the mental health community. The more they get out and share their knowledge, the more likely it is that it will find its way into the public domain.

Good sources allow journalists to write informed stories. That imposes an obligation on the media to seek out knowledgeable commentators, but it also imposes an obligation on mental health organizations to reach out to news outlets and get to know writers and broadcasters. It doesn't matter which side takes the initiative.

Discarding assumptions can unblock the channels of communication. Why shield a person with mental illness from the media without asking if there is a way to protect his or her dignity? Why presume journalists have no interest in mental illness when they may just be embarrassed by their ignorance? Why conclude that one run-in or rebuff is a typical media encounter?

There has been progress over the past 25 years. No member of the media would use a term such as lunatic, retard or insane asylum today. Very few news outlets would wilfully denigrate a person with a psychiatric disorder. In most cases, individuals who take the risk of talking about their own or a loved one's experience of mental illness are treated with respect.

There is still too much silence, too much fear and too much ignorance. But they are not immutable. With effort, persistence and straightforward communication, prejudice can be scaled back.

*Carol Goar is a columnist with the Toronto Star.

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HUMAN RIGHTS OF THE MENTALLY ILL

Julio Arboleda-Flórez* and David N. Weisstub **

Awareness about the high prevalence of mental conditions worldwide and their costs to national economies, let alone the suffering and dislocation in the lives of those affected and their families has accelerated the momentum for mental health law reform. These reforms, however, will not be more than tinkering if a review of the human rights of mentally ill patients is not included. For, while the protection of the human rights of mentally ill patients has been a matter of international concerns for over the past several decades, the actual plight of mentally ill patients does not seem to have improved.

Stigma and Discrimination

Stigma, prejudice and discrimination have been identified as the reasons for most of the difficulties mentally ill patients face when they are clinically ready to reintegrate into society.[1] While stigma and prejudice are attitudes, discrimination is the active denial of entitlements and rights that are ordinarily enjoyed by most citizens. Stigma, prejudice, and discrimination are closely related and tightly interwoven social constructs that are observed across all classes and social groups. Stigma and prejudice are important social attitudes that hinder reintegration of mentally ill patients to their communities, but it is discrimination that leads to denial of rights, especially human rights, that causes the most difficulties.

Stigma develops within a social matrix of relationships and interactions and has to be understood within a three-dimensional axis labeled perspective, identity and reaction.[2] Mentally ill patients usually score high in these dimensions. In addition, the public tends to have stereotypical views of mentally ill patients as violent and unpredictable. The association between mental illness and violence helps to perpetuate stigmatizing and discriminatory practices against mentally ill persons and is only one of the many negative stereotypes and prejudicial attitudes held by the public about them.[3] Furthermore, to the extent that many mental conditions are chronic and incapacitating, mentally ill persons can hardly migrate out of the grip caused by negative social attitudes. The result is social annihilation, a constriction in the lives of the mentally ill that prevents them from full re-integration into their communities and from participating in social activities.

Kelly describes "structural violence" as an insidious condition of discrimination and abuse that in essence translates into "anti-rights" for the mentally ill.[4] For example, mentally ill patients have the anti-rights to remain homeless in the streets where they might freeze to death on winter nights, to be unemployed, or to be confined to a permanent condition of poverty and dependency on charity. Mentally ill patients may also be disproportionately robbed, mugged, raped, beaten up or murdered in the streets where they sleep for lack of proper accommodations. Should they react violently, many times in self-defense, they are labeled dangerous and sent to prisons. Mentally ill patients have in effect been granted the anti-right to be criminalized and to receive treatment, if any, in prisons and penitentiaries, as opposed to hospitals, where most citizens expect to go if they fall ill.[5] The facile manner in which mentally ill patients have been criminalized reinforces the stigmatizing attitudes in society. This has fuelled further fears that they are dangerous and unpredictable, and has led to further calls for expansion of controls via commitment legislation.[6,7]

Unfortunately, by virtue of their disabilities, mentally ill patients tend to be powerless and lacking in motivation to seek redress to their problems. Poverty, political disenfranchisement, and a scarcity of champions that could speak for them compound the plight of mentally ill patients in modern advanced societies.

International Rights

International sources of human rights recognize both negative and positive rights. Negative or "first generation" rights include those that preclude interference with a protected freedom, and prevent the state from certain proscribed actions. On the other hand, positive or "second generation" rights impose mandatory obligations upon states. National systems in countries with advanced mental health legislation, such as Canada, have provided substantial protections for mentally ill patients in institutions so that seldom are they abused in their bodily integrity or their freedoms abrogated. Similarly, countries with advanced economies have also provided significant civil and constitutional protections with respect to the positive rights of its citizens, including those who suffer from mental conditions. The same, however, cannot be said with respect to entitlements to provision of social services.[8]

Louise Arbour, the United Nations High Commissioner for Human Rights, underscored the importance of expanding our vision, both nationally and internationally, of fundamental human rights:

> Recognizing the status of economic, social and cultural rights as justiciable entitlements is crucial to honouring the political, moral and legal commitments undertaken by States when the international bill of rights was adopted.[9]

Her comments, while reaffirming the conception of positive social entitlements as justiciable human rights under international law (as enshrined in such conventions as the *International Convention on Social, Economic and Cultural Rights*)[10] also underscore the failure of states to give meaningful effect to second generation rights. As a Justice of the Supreme Court of Canada, and a frequent dissenter with respect to the ambit of social rights under the *Canadian Charter of Rights and Freedoms (Charter),*[11] Arbour has gauged the shortcomings of national legal systems in this respect. Her observations are particularly apposite with respect to the human rights of persons with mental illness; although there have been significant advances with respect to the negative or first generation rights of such persons over the last twenty years, positive or second generation social rights have not fared so well.

Advancements of human rights for mentally ill patients have taken the form of both binding and non-binding international norms, as well as proposals for domestic legislative reform, via treaties such as multilateral conventions promulgated by international organizations, particularly the United Nations, or through *customary norms*, which have their origins in state practice and *opinio juris*.[12] Human rights under international law, however, have advanced the furthest with respect to negative rights as applied to states obligations (for example, the *International Covenant on Civil and Political Rights*,[13] although international law is beginning to constitute a source of positive entitlements as well. In this regard, the most significant international source of a 'right to health care' is found in Article 12 of the *International Covenant on Economic, Social and Cultural Rights*.[14]

Covenants are, of course subject to the limitation that, in order to be effective for citizens domestically, they have to be given expression in the national law of the country whose citizens seek to enforce such rights. In Canada these rights are covered under the *Canada Health Act*.[15] Furthermore, a significant development with respect to the development of positive rights to health care is found in the *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care*.[16]

Human Rights in Canada

At the national level in Canada, the fundamental rights of mentally ill patients, both positive and negative, are enforced in two primary ways. Legislation and, in some contexts, government action can be challenged in the courts by way of constitutional challenge; the principal basis of such challenges is an alleged violation of the *Charter*, which enshrines the fundamental rights and freedoms of all Canadian citizens. Pursuant to section 52 of the *Charter*, any law inconsistent with the *Charter*'s provisions is of no force or effect, and can be struck down by the courts. A related, though distinct, method of protecting the rights of mentally ill patients is the avenue of judicial review, whereby the decisions of some administrative boards or government agencies are subject to review by the courts. Both of these methods of judicial intervention have had important consequences for the advancement of patient rights in Canada. In regard to the *Charter*, several sections are relevant to rights of the mentally ill, specifically section 15(1) of the *Charter* which prohibits discrimination on the grounds of "physical or mental disability.".

The development of Review Boards and Consent and Capacity Boards is linked to the necessity of living within the proscriptions of the *Charter*. Landmark cases such as *R. v. Swain*,[17] *Winko v. B.C. (Forensic Psychiatric Institute)*[18] and *R. v. Demers*[19] have hinged on the *Charter* to defend rights that had previously been hard to enforce. For example, section 7, which protects a person's right to life, liberty and security of the person, has been invoked to limit the ambit of the *parens patriae* doctrine, whereby the state assumes custody over minors and persons deemed incapable for the purposes of consenting to medical procedures considered unnecessary such as in the case of *E. (Mrs.) v. Eve*.[20] Meanwhile, section 9 protects the individual against arbitrary detainment and imprisonment and section 10 provides safeguards regarding right to counsel and need to inform a person of this right.

Sections 7 and 15 can to some extent be used to advance positive rights. The courts, however, have been rather reluctant to extend positive entitlements to general classes of individuals under the *Charter*, such as in the case of *Gosselin v. Quebec (Attorney General)*, where the court ruled that:

> Nothing in the jurisprudence thus far suggests that s. 7 places a positive obligation on the state to ensure that each person enjoys life, liberty or security of the person. Rather, s. 7 has been interpreted as restricting the state's ability to deprive people of these.
>
> ...
>
> One day s. 7 may be interpreted to include positive obligations. ... The question therefore is not whether s. 7 has ever been — or will ever be — recognized as creating positive rights. Rather, the question is whether the present circumstances warrant a novel application of s. 7 as the basis for a positive state obligation to guarantee adequate living standards.
>
> I conclude that they do not.[21]

Similarly, such reluctance was also in evidence in the case of *Auton (Guardian ad litem of) v. British Columbia (Attorney General)* where the Supreme Court of Canada continued with a restrictive interpretation of the *Charter*.[22] In this particular case, the parents of a severely autistic child argued that the B.C. Legislature's refusal to fund a particular form of behavioral therapy constituted a violation of their child's equality rights under the *Charter*. Justice McLachlin noted:

> One sympathizes with the petitioners, and with the decisions below ordering the public health system to pay for their therapy. However, the issue before us is not what the public health system should provide, which is a matter for Parliament and the legislature. The issue is rather whether the British Columbia Government's failure to fund these services under the health plan amounted to an unequal and discriminatory denial of benefits under that plan, contrary to s. 15 of the *Charter*. Despite their forceful argument, the petitioners fail to establish that the denial of benefits violated the *Charter*.

In a different line, although a great deal of discretion is granted to different administrative boards in the Canadian context with respect to the involuntary treatment of mentally ill patients, the decisions of such boards are nevertheless subject to judicial scrutiny. The recent decision of the Supreme Court of Canada in the case of *Starson v. Swayze*[23] ("*Starson*")is illustrative of the importance of judicial oversight of the decisions of substitute decision makers where persons with intellectual disabilities are deemed incapable of accepting or refusing treatment.

Under the Ontario *Health Care Consent Act, 1996*, a person found incapable can be treated without that persons consent. A finding of incapacity involves a determination by a physician that the patient is unable to comprehend both information relevant to treatment, and the consequences of failing to adhere to this course of treatment. In *Starson*, the appellant, Professor Starson, had been found incapable and was forced to follow a course of treatment which involved the prescription of medication, including mood stabilizers and neuroleptics. Starson appealed the physician's determination of incapacity to the Ontario Consent and Capacity Board, which upheld the physician's determination. An application for judicial review of the Board's determination was brought before the Superior Court of Ontario, which overturned the Board's decision. Both the Court of Appeal for Ontario and the Supreme Court of Ontario upheld the Superior Court's decision.

In *Starson*, the Supreme Court held that the Board's decision was subject to review on a standard of reasonableness. Applying this standard, the Court found that the Board's determination with respect to incapacity was not supported by the evidence. While Starson did not qualify his condition as an illness, he recognized that his brain functioning was not typical. Further, the Board erred in failing to directly ask Starson whether he was aware that his condition would deteriorate without adhering to the proposed course of treatment. Finally, the Board erred in applying the test for capacity; it based its decisions, in part, upon its opinion of the patient's best interest Accordingly, "[t]he Board improperly allowed its own conception of the respondent's best interests to influence its finding of incapacity." [24]

The decision is important, insofar as it reinforces the restrictions placed upon the Capacity and Consent Board with respect to the ambit of its jurisdiction. Specifically, the Court emphasized that the Board's mandate was not to determine the best interests of the patient, but to adjudicate the capacity of the person at issue.

Conclusion

Given the difficulties mentally ill patients experience in voicing their needs, and despite advances in the protection of negative rights in the Canadian context, those concerned about rights of the mentally ill in Canada should keep a watchful eye both in defence of negative rights already obtained, and most especially in the implementation of positive rights and social entitlements for mentally ill patients. Advocates for the mentally ill in Canada should lobby for administrative and legislative reform by Parliament and the provincial legislatures.

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ZONED OUT: RESTRICTIVE MUNICIPAL BYLAWS AND PSYCHIATRIC SURVIVOR HOUSING

Lilith Finkler *

Psychiatric survivors rarely consider land use law a crucial concern. Zoning restrictions, however, such as minimum separation distance requirements, have a disproportionately negative impact on psychiatric survivor tenants. Group homes often provide housing to psychiatric survivors. Minimum separation distance requirements stipulate that group homes must be a specified minimum distance apart. If group homes are deemed too close, the second proposed home may not be established at the desired location. Zoning bylaws, therefore, can limit psychiatric survivor housing.

In the 1960s, when group homes were first established, Ontario municipalities required site-specific zoning bylaw amendments.[1] Organizations that established group homes applied for amendments on a case-by-case basis. Public meetings, required under the *Planning Act*,[2] offered opportunities for prospective neighbours to oppose housing developments. By 1986, Toronto bylaws permitted group homes "as of right" in residential areas, subject to separation distances.[3] Group homes were then routinely permitted; a zoning bylaw amendment was no longer required. This change eliminated the statutory requirement for public meetings. Minimum separation distances were seen as a "balance," a preventive measure to permit group homes and ensure no one neighbourhood was inundated with social services or their recipients.

An examination of Ontario city bylaws revealed that, as of April 2007, 42 of 45 (93%) cities enacted group home bylaws. 35 of 42 (83%) cities also enacted separation distance requirements. Table #1 lists the cities and bylaws. Inconsistencies exist in the application of minimum separation distance requirements. For example, Mississauga (population 700,300) and Quinte West (population 41,000) both have separation distances of 800 metres. This inconsistency illustrates the arbitrariness of separation distances. Larger cities, one imagines, would enact greater distance requirements as group homes could be spread over a wider area. Smaller cities with compact central business districts would need shorter distance requirements to ensure proximity to local amenities. However, as the chart below illustrates, such logic has not guided application of separation distance guidelines.

City	Minimum Separation Distance	# of Metres
Barrie	yes	Not specified
Belleville	yes	250 m
Brampton	yes	120 m
Brantford	yes	180 m
Brockville	yes	215 m
Burlington	yes	400 m
Cambridge	yes	200 m
Clarence-Rockland	no	------
Cornwall	no	-------
Dryden	yes	200 m
Elliot Lake	No group home bylaw	--------
Guelph	yes	100 m
Hamilton	yes	300 m
Kawartha Lakes	yes	300 m
Kenora	yes	500 m
Kingston	yes	250 m
Kitchener	yes	400 m
London	yes	Not specified
Mississauga	yes	800 m
Niagara Falls	yes	350 m
North Bay	yes	200 m
Orillia	No group home bylaw	--------
Oshawa	yes	500 m
Owen Sound	yes	Not specified
Pembroke	yes	365 m
Peterborough	yes	300 m
Pickering	No group home bylaw	-------
Port Colbourne	yes	300 m
Quinte West	yes	800 m
Sarnia	yes	200 m
Sault St Marie	no	-------
St Catherines	yes	300 m
St Thomas	yes	75 m
Stratford	yes	250 m
Sudbury	no	--------
Thunder Bay	yes	240 m
Temiskaming Shores	yes	200 m
Thorold	yes	458 m
Timmins	yes	300 m
Toronto	yes	-------
Vaughan	yes	300 m
Welland	no	-------
Windsor	no	-------
Woodstock	no	-------

Table #1 Current Minimum Separation Distance Bylaws in Ontario

Sometimes, bylaws stipulate varying separation distances for different types of group homes. For example, in Vaughan, "Group Home Type 1" which houses psychiatric survivors is subject to 300 metre separation distances. "Group Home Type 2" provides housing within a corrections context and is subject to 1000 metre separation distances.[4] Clearly, Vaughan uses separation distance requirements to regulate particular types of people by limiting types of housing. Vaughan bylaws do not mention structural differences between housing types. It is inhabitants and regulatory regimes under which group homes are administered that differentiate them.

Some cities measure distances from property line to property line; others measure them from structure to structure. Measuring property line to property line increases required distance between homes, exacerbating difficulties in locating suitable sites for housing. Some cities employ radial separation distances rather than rectangular ones, as is the case in Ottawa.[5] This difference in measurement form may comply with local topography. However, its use also highlights methods by which municipalities may increase distance between group home locations. Finally, group homes may be subject to different separation distances in a municipality's downtown than when located in outskirts of the same city.[6]

Bylaws of only three cities - Elliot Lake, Orillia and Pickering - remain silent on group homes and, consequently, require site-specific amendments. Orillia's silence is particularly disconcerting. Orillia is the closest city to Huronia Regional Centre, an institution for persons with developmental disabilities which is scheduled to close by 2009.[7] Despite the government's intention to relocate disabled inhabitants to group homes, Orillia has not enacted group home bylaws. This municipal policy forces housing developers to initiate site-specific applications, slowing down deinstitutionalization.

Typically, municipalities insist that separation distance requirements disperse group homes and, therefore, benefit both psychiatric survivors and their neighbours. First, separation distances encourage community integration.[8] Second, they decentralise and enforce equitable distribution of social services. Similarly, planners depict minimum separation distances as preventing an over concentration of group homes.[9] The term "over concentration" describes a high density of social services in particular vicinities. Minimum separation distances are, therefore, a response to perceived clustering.[10]

Studies that investigated psychiatric survivors living in community residences, however, have concluded that physical integration has not guaranteed social integration. Being in space does not mean being considered "in place."[11] This conclusion challenges the idea that implementation of separation distance requirements facilitates community integration. Dispersing group homes physically does not result in dispersing tenants socially.

Dispersing group homes may exacerbate social isolation and limit tenants' ability to access resources. Organizations in smaller communities may have difficulty locating their premises close to local amenities.[12] Planners initially recommended implementation of separation distances in an urban context. Application of separation distances to small town and rural locations is inherently problematic. In addition, separation distances may allow privileged homeowners to avoid contact with psychiatric survivor neighbours.[13] Spatial deconcentration may assist planners to ignore systemic discrimination.[14]

Minimum separation distance bylaws maintain segregation by reinforcing opponents' power to determine where psychiatric survivors live. If housing providers wish to build in an area and another residence exists within the separation distance, providers must apply for a minor variance to a municipal Committee of Adjustment. If the application is denied, developers can appeal to the Ontario Municipal Board (OMB), an administrative tribunal rendering land use decisions.

OMB adjudicators have upheld minimum separation distances in principle[15] but typically exempted individual housing projects.[16] Adjudicators sometimes concluded that the separation distance should not be applied because physical attributes separated one neighbourhood from another.[17]Alternatively, adjudicators determined separation distances were applicable to one group home type but not another.[18] One adjudicator hinted that implementation of a specific separation distance might be discriminatory. [19] Because OMB Members are not bound by previous tribunal decisions, there has been adjudicative inconsistency.

Such inconsistencies can discourage appeals. Legal processes extend development timelines and increase costs. It is cheaper to negotiate, even ingratiate, oneself with the opposition, rather than proceed legally. Developers consequently may "cream" applicants and admit tenants unlikely to offend opponents.[20] Developers may describe tenant profiles to neighbours seeking tentative approval.[21] They may compromise architectural design by eliminating overlook or reduce visibility through installation of visual buffering.[22]

Scholars whose research investigates psychiatric survivor housing preferences indicate the majority of survivors wish to reside in their own apartments.[23] Psychiatric survivors living independently in apartments may integrate successfully in their neighbourhoods. From their perspective, group homes could be eliminated in favour of independent housing. Separation distance requirements would not be a relevant concern. For other psychiatric survivors, however, communal life offers an alternative to social isolation.[24] Group home tenants are friends and, sometimes, family for one another.[25] For this latter group, elimination of separation distances could facilitate psychiatric survivor relationships.

Nonetheless, dictating to psychiatric survivors that community integration is "good" for them reproduces the very power dynamics the psychiatric survivor liberation movement has sought to challenge.[26] As Barbara Everett discussed in her book, professionals have often directed psychiatric survivors lives:

> Those in power seek control over the less powerful, by force, if necessary, employing an "it's for your own good" justification designed to elicit both compliance and gratitude and creating an invisible web of hegemonic control.[27]

Clearly, restrictive zoning, such as minimum separation distance requirements, impact negatively upon psychiatric survivor housing. Advocates can successfully challenge offensive bylaws in multiple forums. Simultaneously, however, a critique of group homes would enrich the challenge by incorporating an analysis of psychiatric survivor/provider/municipal relations.

* Lilith Finkler is a PhD Candidate, Dalhousie University. Thanks to Professors Jill Grant and Howard Epstein for their comments on an earlier version of this article.

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NOWHERE TO TURN: THE EROSION OF PATIENTS' RIGHT TO COMPLAIN

André Marin [*]

In keeping with the title of the Psychiatric Patient Advocate Office's special report, "*Honouring the Past, Shaping the Future: 25 Years of Progress in Mental Health Advocacy and Rights Protection,*" I would have liked to write about the many advances in ombudsman oversight in the health care field over the past 25 years.

Unfortunately, when it comes to patients' rights to complain, the reality is more one of regression. When the Office of the Ontario Ombudsman was established in 1975, it provided millions of ordinary citizens with a much-needed avenue to address problems with provincial organizations. We still do that today – and our investigations have sparked many dramatic improvements that touched people across the province and were welcomed by the government itself. But, over time, many of the most vulnerable people in our society, including those with mental illness, have found that avenue closed to them, through no fault of their own.

Under the *Ombudsman Act,*[1] patients in provincial psychiatric hospitals are entitled to complain to me. The *Ombudsman Act* hasn't changed, and neither has my Office – it's the government's mental health strategy that was dramatically altered. Before 1998, patients in 10 provincial psychiatric hospitals across the province could access the Ombudsman's Office. Now, nine of those have been divested by the provincial government to the hospital sector – and hospitals remain out of my jurisdiction.

Unfortunately, Ontario remains the only province in Canada whose ombudsman has no mandate to investigate services provided by public hospitals. There is no effective, independent, investigative oversight of hospital administration, period.

It is not as if successive governments have been unaware of this accountability gap. As early as 1975, Ontario's first Ombudsman, Arthur Maloney, called for his mandate to be extended to hospitals, and his successors have followed suit. We have worked to alert policy makers to the fact that there is no independent, effective system in place to deal with citizens' complaints about hospitals and other care facilities. I believe that in order to ensure public confidence in the health care system and to protect its users, the Ombudsman's mandate should be modernized to include this critical service area. But here we are, more than three decades later, and no significant progress has been made.

Today, our Office retains the ability to address complaints from patients at the Penetanguishene Mental Health Centre, the last of the provincial psychiatric hospitals. All other patients languish in the same situation as every other Ontarian who has a complaint about a hospital – with no right to seek assistance from the Ombudsman and nowhere to turn.

It is frankly astounding that our hospitals, which provide an essential public service and receive billions of dollars of public funding each year, continue to escape the scrutiny of the Ombudsman's Office, despite its mandate to oversee some 500 government ministries, corporations, agencies, boards and commissions. While the Auditor General was given authority to examine financial issues in hospitals as of April 1, 2005 – a laudable step towards greater accountability – this does little to address the issues of deep personal consequence that hospitals raise for so many Ontarians. It is the day-to-day operation of hospitals that has the most profound impact on their lives; the manner in which they and their loved ones are treated when they seek and receive crucial health care services. Yet their complaints about maladministration in hospitals and long-term care facilities can't be investigated. I know – in the 2006-2007 fiscal year alone, my office was forced to turn away 237 of them.[2]

The Ombudsman's Office does have the power to review the Ministry of Health and Long-Term Care's role in regulating long-term care homes and in providing hospital services. We can refer complaints about medical professionals to their respective self-regulating bodies. But we *cannot* consider complaints about poor service, delays, inconsistent application of policies, administrative errors or other matters relating to the hospitals themselves.

In recent years, there have been a few isolated occasions when this barrier to independent oversight has opened a tiny crack; for instance, when the provincial government found it necessary to take direct control over individual hospitals through the appointment of supervisors. This has occurred recently with respect to the William Osler Health Centre, Scarborough Hospital, Stevenson Memorial Hospital and Huronia District Hospital. For the period that a hospital is run by a government administrator, the Ombudsman can accept and investigate complaints about that hospital. But this is clearly a short-term and *ad hoc* situation that only serves to emphasize the problem, since it gives a few patients the right to complain for a brief time, but does nothing for the vast majority.

The people who try to complain to our Office about hospitals or long-term care facilities are often vulnerable individuals or their families. Some hospitals have chosen to set up an internal "patient ombudsman" to deal with complaints, but this is clearly no substitute for independent investigative review. In fact, we have heard from individuals who allege that they experienced retaliation when they raised concerns internally, from the very institutions that are supposed to provide care. Patients are entitled to an external, independent and credible investigative body precisely so they do not have to face this kind of situation.

It is disheartening to watch other jurisdictions forge ahead of Ontario in establishing oversight of such an important part of the public sector. In 2006, both Quebec and Alberta extended the authority of the provincial ombudsman (*"protecteur du citoyen"* in Quebec) to cover investigations relating to hospitals, long-term care facilities and nursing homes. That same year, Andrea Horwath, Ontario Member of Provincial Parliament, introduced a private member's bill that proposed extending the Ontario Ombudsman's authority to include hospitals and long-term care facilities. However, this effort did not receive government support and the bill died when the House was prorogued.

While mental health advocacy and rights protection may have advanced in Ontario over the past 25 years, and certainly the work of the Psychiatric Patient Advocate Office has contributed to this forward momentum, there remains an accountability backwater in Ontario's heath care system. All patients, and particularly those most vulnerable, those suffering from mental disabilities and the aged, deserve the right to complain to the Ombudsman when they believe they have suffered from abuse or maladministration at the hands of hospitals in this province. After all, this is the same right enjoyed by the tens of thousands of Ontarians who complain to me about virtually every other area of government endeavour.

My hope for the future is that Ontario will one day be suitably chastened by its last-place finish in the oversight field to pick up its pace and move to the head of the oversight pack. Ontarians deserve nothing less.

[*] André Marin is the Ombudsman of Ontario. Prior to his appointment as Ombudsman in 2005, Mr. Marin served as Canada's first Ombudsman for the Department of National Defence and the Canadian Forces. He was also the Director of the Special Investigations Unit of the Ontario Ministry of the Attorney General.

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INDEPENDENT ADVOCACY AND RIGHTS PROTECTION – IMPROVED QUALITY OF CARE AND LIFE FOR PATIENTS

Allen Prowse*

The protection of individual human rights is one of the keystones of democratic societies. The pursuit of this value in the context of societal rights and freedoms has been a centuries old preoccupation in North America and worldwide.

While the concept of ensuring the protection of individual rights has been the subject of much debate, concern and consensus, organizing the social and administrative systems which bring that worthy goal to life has challenged legislators, clinicians, administrators, policy makers and advocates for many years.[1]

Bringing these lofty goals to the face to face reality of clients and the caregiver requires a focus on the larger objectives of health care, which include:

- To provide effective care and treatment in the best interests of the client;
- To produce favourable client outcomes; success as defined by both client and caregiver;
- To provide interventions (support, advice, therapy) which are objective and compassionate, respecting the individual's human dignity;
- To provide care and service with the greatest possible transparency while respecting the individual's right to privacy; and
- To be attentive and open to the need to change in response to new knowledge or changing cultural or social environments.

Issues

Ensuring adequate and effective client advocacy as a way of protecting the rights of vulnerable members of society has been a decades long focus of clinicians, advocates, policy makers and legislators.[2]

Patient or client advocacy needs have been traditionally grouped into three main issue categories:[3]

1. Quality of life (social rights advocacy) issues, which include privileges, economic status, privacy and confidentiality, security for patients and their property, recognition of individuality, access to religious services, contact with family and friends, and services in the patient's first language.
2. Quality of care (therapeutic advocacy) issues, such as therapeutic alternatives, second opinions, choice of caregiver, clinical safeguards, information about treatment, access to care-giving persons, discharge plans, and adequate supervision.
3. Self-determination (legal advocacy) issues, for example informed consent, access to clinical records, patients' rights information, review of committal, access to legal services, incapacity determinations, compulsory treatment, and restraint.

The purpose of this article is to reflect on the contributions of independent patient advocacy to the quality of life, quality of care and self-determination of both inpatients and community clients of a regional mental health service organization.

While a significant amount of the literature on advocacy and patient/client rights involves a debate concerning the strengths and weaknesses of internal versus external rights providers, Providence Care has benefited from the decision of the government of Ontario to establish the Psychiatric Patient Advocate Office (PPAO), Canada's first province-wide advocacy program. Olley and Ogloff provided perhaps the most succinct description of the program.

> The provincial Ministry of Health established the program as a new program designed to extend human right protection to psychiatric inpatients. Initially, advocates were assigned to each of 10 provincial psychiatric hospitals. They operate within each facility but report directly to the provincial coordinator of the program. Advocates receive extensive initial and ongoing training from lawyers, consumer advocates, psychiatrists, and other experts on medical and legal issues. Advocates are trained to be competent and knowledgeable about psychiatric and legal issues and to demonstrate good negotiation skills. Advocates have access to facilities and patients both within the hospital and in the community. In general, the goal of the PPAO is to advance the legal and civil rights of psychiatric patients through individual casework and systemic advocacy. This program provides legal representation for patients and addresses less formal daily concerns or complaints associated with residing in institutions or community settings. The PPAO also provides information to patients, families, and others about patient rights and resources that are distributed primarily through posters, brochures, and verbal communication. When a second opinion is required, patients may be referred to external advocacy resources.[4]

Although referrals are accepted from family members, staff, and other patients, advocates act only on the instruction of the patient.

Evaluations of the PPAO have found that the most common complaints from patients pertain to legal issues regarding commitment and detention. Most of the clients are involuntary patients, young, and able bodied. It is suggested that less functional and elderly patients may not have the same accessibility to services, as do other patients. On the other hand, in measuring client satisfaction of those using the program, it seems that program objectives are being met.

Providence Care Mental Health Services

Providence Care's Mental Health Services site[5] is a regional provider of specialized services to adults with serious mental illness in Southeastern Ontario.

As a teaching facility, Mental Health Services participates in the training of students in several disciplines. A number of professional staff hold joint appointments with Providence Care and Queen's University, and conduct clinical research to contribute to the understanding of mental illness and treatment approaches.

Mental Health Services, an accredited 198-bed facility, provides treatment through three clinical program areas: Adult Treatment and Rehabilitation, Geriatric Psychiatry and Forensic Psychiatry. Each program offers a continuum of care – inpatient, outpatient and community – with an emphasis on reintegrating clients into the community at the earliest possible opportunity.

Providence Care and the PPAO – Working Together

The PPAO has knowledgeable and well-trained front line advocates whose work is supported by independent research, training and legal staff. This infrastructure allows advocates to provide not only best practice advice, but also a broader perspective, reflecting various options and approaches which may have been applied effectively elsewhere. In addition, the PPAO also provides information on systemic issues and concerns from a client perspective which have arisen elsewhere and which may represent potential issues in our service settings. In this way the PPAO contributes its knowledge and experience to the ongoing education and information available to Providence Care staff in the delivery of service. Moreover, it puts advocates in the position of being able to contribute possible solutions and alternatives for discussion, which promotes a collaborative environment focused on solutions and quality improvement.

Together, Providence Care and the PPAO bring most, if not all, of the attributes required at the caregiver-client to ensure the protection of individual rights and to maximize the opportunity for client recovery. In combination, they ensure a focus on the following key issues:

- Providing effective care and treatment for the client;
- Producing favourable client outcomes as defined by both the client and caregiver. This is the essence of using a recovery model of care and represents a shared philosophy within which the roles of advocate and caregiver can help and support each other in the delivery of high quality care;
- Provide interventions (support, advice, therapy) which are objective and compassionate and respect the individual's human dignity;
- Provide care and service with the greatest possible transparency while respecting the individual's right to privacy; and
- Being attentive and open to the need to change in response to new knowledge or changing cultural or social environments. This may include information from the PPAO concerning new caregiver approaches, discharge plans or clinical safeguards.

PPAO advocates and Providence Care staff enjoy a tradition of trust and collaboration in terms of their shared efforts to find treatment outcomes and solutions that represent the best achievable outcomes respecting the client's wishes. It rests on shared values of compassion and empathy, treating each person with dignity and respect and attempting to meet their fundamental needs. It is a partnership, which we believe has benefited all of the parties involved.

* Allen Prowse is the Vice President, Mental Health Services and site Administrator for the Mental Health site for Providence Care, in Kingston and has significant experience in mental health service delivery in hospitals, community and government.

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2 Wolkon, G., Moriwaki, S., The Ombudsman: A Serendipitous Mental Health Intervention, Community Mental Health Journal, Vol. 13(3) 1977.

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A PARADIGM SHIFT IN HEALTH CARE QUALITY PROCESSES

Robert Cunningham*

I think that we should declare 2007 'The Year of Governance' and start to put back on the table of the boards not just a request, but an absolute sense of obligation, that learning who does better and then doing at least that well is central to proper stewardship of health care. Until leaders own that problem, I don't think spread is going to happen. The buck stops in the board room.

--*"An Interview with Donald Berwick"*[1]

Advocacy is not an end in itself. The purpose must be to improve the care given to individuals and to groups of individuals within the (mental health) system. As Berwick indicates above, it is necessary to identify who is most directly responsible for "owning" the challenge of making changes to continually improve quality in order for any group to be effective within the overall process.

My comments about the Psychiatric Patient Advocate Office (PPAO) will speak to my own interactions with the PPAO during my time as an Administrator within the Provincial Psychiatric Hospital (PPH) system in Ontario and now from the perspective of a Chief Executive Officer in a public hospital that assumed responsibility in 2005 for operating a former PPH. I will outline the dramatic changes that have occurred over the last 20 to 25 years that are directed to improving care. I will conclude with some questions that might bear attention from the PPAO.

My introduction to the work of the PPAO occurred in 1986, when I took the position of Administrator of St. Thomas Psychiatric Hospital. The introduction was by way of senior staff relating to me the difficult relationships with the first advocate at the hospital. Some research gave me the background to the PPAO as well as an overview of the ways that advocacy could be practised. It was not clear whether the situations being described represented the style in which the PPAO had determined to operate ("in your face"), attempts by the staff to indicate that the advocate function was not needed ("we're doing a good job!"), or personality clashes with the individual ("can't we all just get along?").

More than two decades on, I have worked with more than a dozen hospital-based advocates, as well as leaders in the PPAO. I long ago concluded that the answer I was seeking was not straightforward: all three possibilities applied then and they continue to apply, although the relative occurrence of each explanation has changed.

Troublesome issues with the operation of the PPH system in Ontario, or for that matter any of the government operated mental health services in North America, have been documented in government reports, media coverage and through the distinctive perspectives of consumers and those that refer to themselves as psychiatric survivors. In my experience, the single biggest problem with PPHs was their history as asylums, as opposed to treatment facilities. Other factors slowed the introduction of improvements in care: the provincial civil service environment, which had no sense of the challenges of operating a hospital; the perpetually inadequate remuneration of clinical staff; and the lack of a coherent provincial vision for the provision of mental health services.

During those early years there was only one significant external quality mechanism – the voluntary process of accreditation through the Canadian Council on Hospital Accreditation (now the Canadian Council on Health Services Accreditation). The PPHs in Ontario did not participate in this process consistently until the 1970s. The *Public Hospitals Act* did not apply to these hospitals. The *Mental Health Act* and the *Mental Hospitals Act* provided only a modicum of process standards.

Internally, PPHs could and did model the *Public Hospitals Act* and associated regulations. The quality mechanisms from this statute – chiefly a peer driven medically based quality of care process - were used to advance quality of care. Absent a Board of Directors, mechanisms such as these were not as effective as in public hospitals.

It is not surprising that the introduction of independent advocates into the setting of the PPHs resulted in the sort of conflicts that I described above. It was a new quality mechanism which operated at the level of individual patients. Unlike most types of quality mechanisms, this approach depended heavily on the skills of the individual advocate. The best of the advocates that I worked with showed an ability to tailor their interventions so that they built relationships with clinicians, managers and senior leaders to accomplish change at the individual, program and hospital levels. I always understood that some confrontational actions were also necessary when intransigent clinical staff were involved. Having described the process as well as the limitations that I saw, I must be clear in saying that this advocacy made a difference. Care approaches and quality improved.

Fast forward to 2008 in Ontario where there is a reshaped health care system and better attention to both the funding of mental health care delivery and to a coherent system of service delivery. Perhaps most importantly, society expects quality and demands transparency in its health care system. Governments are acting to legislate and regulate these matters.

Let's be more specific. All but one of the former PPHs now operate under incorporated Board governance with explicit legal direction from not only the *Public Hospitals Act*, but also the new concepts contained within the *Commitment to the Future of Medicare Act, 2004* and the *Local Health System Integration Act, 2006*. Boards of Directors are now directly challenged to step up in the manner Berwick describes.

New quality groups have been created and existing groups are evolving. For example, accreditation processes have effective survey and data gathering approaches that demand ongoing efforts on the part of hospitals to improve quality of care, safety for patients, community relationships and so on. Patient safety organizations in both Canada and the United States have effective and voluntary campaigns that are making a difference in how both physical and mental health care systems attend to safety issues (e.g., medication reconciliation).

Many health care organizations directly employ staff in the capacity of patient representatives; their role is to advocate for patients and families with concerns about their care.

The Ministry of Health and Long-Term Care now has the role of steward of the system. It is creating regulations and policies that detail a number of safety and accountability responsibilities for hospital Boards and CEOs. Regulations include requirements to disclose to a patient the details of any adverse event that has occurred. It will be mandated soon that all hospitals publish specific quality and safety indicators. Leading organizations, like the University Health Network and Sunnybrook Health Sciences Centre, are ahead of the curve in this area. They already publish information about adverse patient events and other quality issues with benchmark information for easy comparisons.

Specifically within speciality mental health facilities, several facilities (Centre for Addiction and Mental Health, St. Joseph's Health Care London, Northeast Mental Health Centre) are about to or have formally adopted Patient Bills of Rights which have been developed by consumers. There is close attention to client centred care principles, supported by patient councils that have survived and prospered under board governance. Formal adoption of recovery models and practices of care is the latest extension of patient centred care to occur. Increased employment of individuals with direct experience of the mental health system as both clinicians and as peer support staff is a tangible demonstration of commitment to improving care.

These highlights demonstrate the range of initiatives that are now in play to assist hospital boards, leaders, managers and clinical staff to create an environment where care and safety can continually improve. The contrast with the world of the PPHs of the 1970s and 1980s is stark.

If Berwick is correct that hospital Boards of Directors are at the centre of quality improvement, then the reporting relationship of the PPAO to the provincial government may not be optimal if it wants to relate closely to Boards regarding its advocacy of improved care.

Over its 25 years of operation, the PPAO and its staff have crafted a well-deserved reputation for effective advocacy. However a number of major changes have occurred. It could be said that these changes collectively represent a paradigm shift in the system of public reassurance over quality care and safety. In this case it would be logical for the PPAO to consider how to adapt. I will close with several questions for consideration:

- Are hospital Boards which operate specialty mental health services really at the core of quality assurance in mental health care?
- If so, does the PPAO have an appropriate profile and relationship with these Boards?
- What mechanisms are open to the PPAO to build better relationships in this area?
- Is there a risk that this approach would compromise the core principles of the PPAO?
- Is the current operation of the PPAO with regard to data gathering, analysis and reporting in keeping with best practices now in place within the quality measurement and safety spheres?
- How can the province-wide PPAO role of advocating with the Ministry of Health and Long-Term Care and with other provincial structures be protected as changes are considered?

*Robert Cunningham is President and Chief Executive Officer of the Northeast Mental Health Centre

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1 *Joint Commission Journal on Quality and Patient Safety 2006;32(12):666.*

REFLECTIONS OF THE PAST

Colleen Woodruff* and Deborah MacLean**

It was May 1983 and the 10 provincial psychiatric hospitals were about to receive a gift – the Psychiatric Patient Advocate Office (PPAO). Each hospital was getting an independent Patient Advocate, employed by the Ministry of Health (expect for what is today known as Mental Health Centre Penetanguishene and the Centre for Addiction and Mental Health – they were getting TWO Advocates!) To help the patients and staff better understand the role of the Advocate, an article was printed in the individual hospital newspapers outlining the principals, goals, objectives and background of "this province wide psychiatric patients' human rights program." The article read as follows:

> The program operates on the principal that an advocate service must be provided to ensure that recipients of care under mental health services are not deprived of their basic rights as citizens. To this end, full time advocates have been assigned to each of the ten provincial psychiatric hospitals to act on the therapeutic, social and legal spheres under the Federal *Charter of Rights and Freedoms*, the Ontario *Mental Health Act* and the Ontario *Human Rights Code*. The advocates report directly to the program coordinator, Dr. Tyrone Turner, and will act independently of the hospital structure and administration. The coordinator will facilitate the program and will make reports to the Executive Director of the Mental Health Division, as well as to the Deputy Minister, a Program Advisory Committee and annually to the Minister and the public. The prime objectives of the advocacy program as mentioned above is the protection of the patients' rights, however, the program's goals reach beyond the task. The advocates while focusing on patients' issues will also interact with staff of all levels and will inform hospital staff, patient families and the community in general, about patient rights. The advocate will fully investigate any patient related complaints and will resolve difficulties through appropriate negotiations.[1]

The Early Days

So, do you really think the hospitals saw the PPAO as a "gift"? No, they didn't. Many hospital staff and administrators were resentful of the fact that the PPAO had been foisted on them by the government and some even saw PPAO staff as "Ministry spies" who were put in place to be critical of their work, how service was delivered and to report back to the Ministry. They failed to recognize that the PPAO was set up as an "arms-length" program of the Ministry and given the authority to "speak freely on issues impacting patients' rights." It became evident that they did not hear or believe what the late Honourable Larry Grossman, Minister of Health, said when he rose in the provincial legislature and said "Mr. Speaker, the Patient Advocates will have and must be seen to have impartiality and independence. They will be there to safeguard a patient's interests, whether legal or health."[2]

In the early days, staff often remarked that "the patients' have all the rights and we have none." Some frontline staff felt disempowered and believed that they were unable to "do their jobs like they had done before." This, combined with a perceived adversarial approach by a Patient Advocate at times, often led to less than positive outcomes for everyone involved, including the client. Regardless of what or how a Patient Advocate conducted themselves, his or her actions were often seen as confrontational, questioning and undermining the authority of hospital staff. It took time and education for staff to recognize the contribution that the PPAO would make in advancing and protecting patients' rights and in addressing quality of care and life issues. But, that was then and we can honestly say that now most hospital staff respect the work done by the PPAO, the positive impact that the organization has had on the system at large and we are now viewed as a resource to patients' and staff alike.

As two people who started with the PPAO all those twenty-five years ago, we'd like to reflect back on the program's development over time. Originally, there were 12 Advocates across the province, plus a secretary in each office. We started out working three days a week. The Advocates came from various backgrounds and disciplines, including a social worker, psychologist, union leader, lawyer and minister. The Advocates quickly gained the trust of the clients. It did not take long for word to spread about our offices, the reason we were there and the work we could do. Many days, in the morning, we would be greeted by clients sitting on the floor outside our office door waiting for nothing more than to chat or to find out about their rights and how they could exercise those rights.

But, over the years, we have also witnessed de-institutionalization and the move from hospital to community-based care and treatment. The hospitals have been downsizing for many years and there are now far fewer inpatient beds available in the mental health system in Ontario. In 1983, the patient population in most provincial psychiatric hospitals was double or triple what it is now. It was not uncommon at the time to have six to eight clients in dormitory style housing on inpatient mental health care units.

Making a Meaningful Contribution

In the early days, there was always a flurry of activity in the hospital as most were self-sustaining communities with opportunities for patients to be involved in housekeeping, cooking, maintenance or even farming. Historically, however, there were also examples of clients being forced to work, against their will and in violation of their rights. This became the justification for eliminating work programs, vocational skills training programs and other activities that promoted skills development. Many clients look back on those years with fondness because they were able to do some work and contribute to the community. For others, it is a period that brings back bad memories of forced labour and being told that they "must" work or do menial labour, even if they didn't want to or have a desire to do so.

Some of our clients kept busy by being involved in many of the various programs and workshops offered through vocational and recreational services in the hospitals. In Kingston, a group of men referred to as the "outside gang" were responsible for maintaining the hospital grounds. This group cleared snow in the winter and cut grass and raked in the summer months. Pay-day was on Fridays and if our memory serves us correctly, the clients received $7.00 a week. It was a major disappointment when the "work gang" lost their jobs resulting in many an idle hour. The clients collectively complained to our office; unfortunately it turned out to be a losing battle as the days of having clients "work" while hospitalized was a thing of the past. In St. Thomas, many clients fondly recall the days when the "Ontario Hospital" was a working farm and a self-sustaining community. Now there are few opportunities to learn vocational skills to prepare them for life outside hospital as they embark on their journey towards wellness and recovery.

Up in Smoke

Smoking was allowed just about everywhere twenty-five years ago. We remember quite vividly walking down the corridors in a "purple haze" of smoke. Staff were allowed to smoke at their desks and we would quite frequently "light up," as well. Today, smoking is prohibited in the hospitals. This turned into a major systemic issue for the Advocates in the current and former provincial psychiatric hospitals. The *Smoke-Free Ontario Act*[3] permits an exemption for tertiary care hospitals to allow smoking in proper ventilated smoking areas but the standards set for these rooms and the cost of retrofitting current facilities is prohibitive. Forgotten in all of this is the client who may consider the facility to be their residence or home. Instead they must smoke out of doors or, in the majority of cases, off hospital grounds, thereby limiting the exercise of this right to those individuals who are not involuntarily detained or otherwise not permitted to leave the hospital.

Psycho-Social Therapy and Earning Privileges

The Advocates with forensic units in their hospitals fought long and hard to do away with a program called psycho-social therapy. It stripped patients of their human dignity, was controlling and restrictive. In order to receive any kind privileges, the patient would have to earn points. Whether you earned or lost points, depended solely on your behaviour and how well you followed the rules. The Advocates were instrumental in helping to squash this program in the late 1980s.

Unfortunately, in many hospitals today, clients are still required to "earn privileges" before they are able to do such things as leave the unit, go for home visits or even engage in some types of programs. The privilege system harkens back to days gone by and as a method of social control to ensure compliance with "the rules." Hopefully, the adoption of a recovery orientation will lead to the abolishment of antiquated privilege systems.

It is hard to believe that wearing street clothes was an earned privilege. When a client was admitted their clothes were taken and they were given pyjamas. This was a provincial systemic issue identified by the PPAO and brought to the attention of the Ministry. In 1990 a letter was sent from the Deputy Minister's office to all hospital administrators directing the hospitals to stop this practice immediately. Although some hospitals did discontinue this practice, others did not. Some hospital's would also put involuntary patients in pyjamas who were at risk of leaving the hospital without permission or who had left the hospital without permission and been returned.

Personal Needs Allowance

Prior to April 1, 1989 the clients in provincial psychiatric hospitals did not receive the Personal Needs Allowance. Back then it was referred to as the "Comfort Allowance." It was thought that persons residing in psychiatric hospitals had all of their needs met and, therefore, did not need any extra money. This was another provincial systemic issue identified by the PPAO and brought to the attention of the Ministry. Our office began the challenge of trying to get the government to change the law in 1983. Many, many letters were exchanged between Mary Beth Valentine, the Provincial Coordinator of the PPAO at that time, to the Minister of Health, and the Minister of Community and Social Services. The PPAO was instrumental in successfully advocating for our clients who had been the subject of such inequity. On April 1, 1989 the clients in provincial psychiatric hospitals received the "Comfort Allowance" in the amount of $112.00. Today the comfort allowance is called the Personal Needs Allowance.

Interestingly enough, the concerns that the clients had 25 years ago are still concerns today, such as financial issues, issues around their medications (e.g., type of medication, the need to take medication), not being fully included in their care plans and discharge planning, and seclusion.

The Evolution of Advocacy

One might say that much has changed, yet much remains the same. Gone are the days when Advocates are seen as the enemy. For the most part, Advocates and rights advisers work in partnership with hospital staff and are viewed as a resource, asset and champions of patients' rights. Staff feel comfortable discussing issues with our staff and very often seek advice from us. Advocates are invited to sit on many hospital committees as *ex-officio* members representing the clients' perspective.

Yes, we've come along way in the past 25 years, but we still have a long way to go as we all work together to insure our clients receive the best care and treatment as we assist them on their journey to recovery.

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[**] Deborah MacLean is a Patient Advocate with the Psychiatric Patient Advocate Office at Regional Mental Health Care, St. Thomas.

Both Colleen and Deborah have been employed by the PPAO from the beginning of the program.

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1 St. Thomas Psychiatric Hospital, The Encounter, June 1983.
2 Advocacy in Psychiatric Hospitals, Evaluation of the Psychiatric Patient Advocate Office, 1987.
3 S.O. 1994, c. 10.

DELIVERY OF ADVOCACY SERVICES IN DIVESTED FACILITIES: WHAT WORKS AND WHAT DOESN'T WORK

Angela M. Martin[*] and Marie V. Taylor[**]

Not having a clear mandate to provide advocacy services in divested facilities has further substantiated the need for a clear legislative mandate for Patient Advocates to advocate on behalf of clients. Advocacy services in a reformed mental health system calls for a delivery of advocacy service model that is provincially coordinated, and enshrined in legislation to ensure that the system is accountable to the people it serves; providing access to advocacy and rights protection services regardless of where care and treatment is received. Since 1983, the Psychiatric Patient Advocate Office (PPAO) has worked for the rights of inpatients in Ontario's former and current and provincial hospitals. Of late, nine of the ten provincial hospitals have been divested. "Divestment" the transfer of governance from the Ministry of Health and Long-Term Care to the Public sector, brought about unprecedented changes in the delivery of advocacy services. Despite these challenges, the Patient Advocates at the PPAO continue to strive and persevere and do what is needed to get the job done with and on behalf of their clients.

We believe that advocacy is essential to a reformed mental health system, whether it be provided in community or hospitals. Its function is to empower and assist consumers in addressing rights-based issues arising from their quality of life, care, treatment, and rehabilitation. We advocate with and on behalf of clients, assisting with their self-identified goals and needs. Advocacy seeks to return or give power to consumers to resolve concerns through a range of education, negotiation, facilitation, and conflict resolution strategies. With relentless tenacity, we push the envelope as far as possible to achieve a "win-win" situation, in keeping with the instructions of our clients. Sometimes the job requires that the Advocate form coalitions with like-minded hospital staff to work together for the advancement of clients' legal and civil rights. Once the Advocate is able to establish this common thread of understanding, the building blocks of relationships and alliances can be formed. Due to the success of these alliances, advocacy has become less adversarial as the Advocates have established relationships with a cross-section of frontline staff, and various levels of management. Clearly, this does not happen overnight, and it requires patience, diligence, and trust between Advocates and staff. The benefits of this approach are reflected in the positive outcomes that are achieved on behalf of our clients.

Advocacy in divested facilities calls for diplomacy from the Advocate, along with a desire to address issues with and on behalf of clients with vigour, vehemence, and commitment. The Advocate uses various skills that involve reasoned discussions, negotiation, mediation, and conciliation. We would rather be seen as diplomats than "watchdogs" using adversarial tactics that are ineffective and polarizes relationships. We are mindful that an overly ardent approach could result in punitive measures for our clients. One should never confuse advocacy that is primarily non-adversarial with avoiding sensitive or controversial issues.

Ongoing education about the mandate of the PPAO and our role has played a critical part in our work. We work extremely hard at providing ongoing education on patients' legal rights and entitlements in facilities. It is evident that the greater the degree of the staffs' understanding about the work we do, the less frequent the need for adversarial measures.

At times, the Advocate encounters barriers when staff are reluctant to revisit their decisions or position on an issue. This impedes opportunities for continuous quality improvement and accountability to clients and stakeholders. We believe it is paramount for facility staff to understand the benefits and added value of the rights protection initiatives undertaken by the Advocates. Our work often helps to mitigate risks when we alert staff of potential risk/liability issues.

With the advent of divestment, the organizational structures of psychiatric facilities were entirely rewritten. Facilities now have a more detailed and intricate reporting structure, and the Advocate may not have established direct contact with the Chief Executive Officer. Facility liaisons vary across the province.

Our perception is that hospitals have adopted a shift in thinking since divestment. This shift is emphasized by the hospital's change in attitude towards the inclusion of the Advocate in discussions that impact our mutual clients. Involving the Advocate from the beginning in discussions about a particular issue allows the process to be more responsive to clients. For instance, we believe that facilities would benefit from the Advocate's input in the development of polices and procedures as it would provide an opportunity for more client input.

The cultural shift since divestment appears to engender a tolerance for the Advocates, but not necessarily acceptance and inclusion. Since divestment, our independence from the facilities we serve is often seen and used as a reason to exclude the Advocates in dialogue around issues impacting our mutual clients.

In keeping with our practice of using the avenue of least contest, in the majority of cases we are able to work with the client and the staff person associated with the issue to resolve the issue. However, there are times when issues must be escalated to a higher level within the PPAO. There are now designated people, assigned at the directorship level, responsible for specific portfolios with whom the Advocate can consult, and/or to whom the Advocate can present issues for discussion.

The PPAO has always held the belief that advocacy must be client directed or based on client instructions wherever possible. It must also be accessible, confidential and independent of the facility they serve. These principles are the cornerstone of social advocacy. While the advocacy work that we do in the facilities was initially focused more on social advocacy, in recent years, we have seen an ever increasing forensic population, and an increase in legal issues. In the past, Legal Aid Ontario had the responsibility of providing duty counsel services to in-patients. Since divestment, most have stopped coming into facilities, resulting in the Advocate having an expanded role in assisting clients with applications to Legal Aid Ontario. Advocates are more involved in assisting clients with complex legal matters including appeals, matters related to immigration, child protection, and family law. The allocation of forensic beds has increased post-divestment. This is reflected in the volume of requests for advocacy services from this segment of our client population. This has impacted service delivery to the non-forensic clients, since responding to legal issues absorbs more of our resources.

Unfortunately, the most vulnerable clients who are unable to give voice to their concerns are less likely to benefit from our assistance. These clients are often unable to contact our office, and in order to fulfill our mandate of providing non-instructed advocacy, we rely heavily on referrals from staff, family members, and substitute decision-makers.

We urge stakeholders, facility staff, families, care givers, and consumer-survivor organizations to build stronger partnerships with us, and to make a renewed commitment to improving client care and treatment, since we believe that this is an important first step in delivering better mental health services. We need to be better connected on a more meaningful and effective level than ever before to build stronger alliances. To improve the delivery of advocacy services in divested facilities it is going to take all of our efforts and a willingness to make a difference in the lives of those who turn to us when they most need help. These individuals often find themselves at the lowest point in their lives, and are dependent on the health care system to be accountable to them in their time of need. As Advocates, we believe with every fibre of our being, that the dignity and value of those who are experiencing the effects of mental illness must be preserved.

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25 YEARS LATER – IS THE PPAO STILL NEEDED?

Steve Lurie*

I can say that I was actually there at the birth of the Psychiatric Patient Advocate Office (PPAO). Health Minister Larry Grossman created the PPAO after his walk through Parkdale with Pat Capponi, a walk that convinced him that not only did we need to improve or create community mental health services and housing, it was also important to ensure that peoples' rights were protected when they were hospitalized under the *Mental Health Act*.

At that time, there were some in the psychiatric survivor community who felt that an advocacy service funded by the provincial Ministry of Health would never have the independence necessary to fulfill a rights protection mandate. There was actually a Canadian precedent for the model Mr. Grossman chose. New Brunswick had legislation on its books that allowed the Minister of Health to appoint inspectors from the community to investigate conditions in psychiatric institutions.

When the PPAO was established, there was some resistance among provincial psychiatric hospital staff, but Dr. Alan Manson's review[1] published a few years after the PPAO began noted that clinical staff actually found it helpful to have someone to bring *their* concerns to. Of course, the PPAO has generally taken its cue from people who have been hospitalized, listened to their concerns and provided advice or advocacy if required.

The PPAO has played a valuable role in safeguarding rights by providing the majority of rights advice in the province to people staying in psychiatric facilities under the *Mental Health Act*. The requirement for rights advice, while guaranteeing the PPAO's existence in legislation, is likely one of the things that has made the mental health legislation consistent with the *Charter of Rights and Freedoms*.[2] So as long as there are involuntary admissions, treatment incapacity decisions and community treatment orders, there will likely be a need for the PPAO.

While the PPAO is funded by the Ministry of Health and Long-Term Care, as are the hospitals and the community agencies providing community treatment orders, the employer is not the service provider. The net effect of this is independent rights advice and advocacy services – there is no potential for conflict of interest because PPAO staff are not accountable to the psychiatric or general hospital. This does not mean that the PPAO is completely independent of the institution, and over the 25 year history there must have been instances when hospital staff felt the PPAO "crossed the line." But, over all, I think the PPAO has been able to provide advice and facilitate solutions using discursive authority rather than "two by four" diplomacy. I recall that the Manson report indicated that in a minority of cases, legal action occurred. One could postulate that without the PPAO, there might have been more legal action, more costs and likely lengthier times to resolve issues.

Beginning in 1987 with Father Sean O'Sullivan's Advocacy Review,[3] the issue of advocacy for all vulnerable people became part of the public agenda. As a participant in that process as a member of the service provider committee, I was convinced that an independent advocacy function would help vulnerable people assert their rights and identify systemic issues. This was based partially on the achievements of the PPAO, as well as the compelling stories of mistreatment and exploitation that surfaced during the review.

When the NDP government created the Advocacy Commission near the end of their mandate, I was a bit surprised that the PPAO was not in favor of becoming part of the Commission. As it turned out the PPAO was fortunate not to be absorbed by the Advocacy Commission, as it was terminated by the newly elected Conservative government in 1995. British Columbia also terminated its advocacy commission during the same period.

During the past 10 years, the PPAO has thrived, in part because it was able to convince general hospitals to have them provide rights advice, and also due to the most recent amendments to the *Mental Health Act* in 2000 which required rights advice for community treatment orders. The PPAO also had a ground breaking pilot project with assertive community treatment teams in Eastern Ontario that demonstrated their ability to help teams focus on empowerment and access to community services for ACT clients.[4]

Twenty-five years later, there is still a need for the PPAO. While hospitals and community agencies are asked to focus their attention on organizational and clinical ethics as part of accreditation, and while the one remaining provincial psychiatric hospital has recourse to the Ombudsman of Ontario, and the other hospitals have access to client services offices, there is still a need to inform people of their rights under the mental health and related health legislation and mediate conflicts or miscommunication between clients and hospital staff. There is still work to be done to help people access community supports such as Ontario Disability Support Program benefits and community mental health services, where dispute resolution services are the exception rather than the rule.

While all organizations should have dispute resolution capacity, knowing that there is an outside agent who could intervene might spur the development of internal mechanisms. There is also still a role for systemic advocacy as represented by the PPAO's current participation in the coalition regarding police records checks for people who have been apprehended by police pursuant to the *Mental Health Act*. This is a significant development as the PPAO is sharing leadership and working along side consumer groups such as the Ontario Council of Patient Councils.

While hospital and community mental health funding has been devolved to Local Health Integration Network, a case can be made for maintaining the PPAO as part of the Ministry of Health and Long-Term Care, consistent with its stewardship role as a watchdog regarding the rights of psychiatric patients, the role it was given 25 years ago by Mr. Grossman. It is unlikely that Local Health Integration Networks could carry out this function, given their current resources, responsibilities and stage of development.

I look forward to the 50th anniversary celebrations, as the PPAO continues its role as the canary in the coal mine, while ensuring there is still oxygen in the mental health system!

*Steve Lurie is the Executive Director of the Canadian Mental Health Association, Toronto Branch and Chair of the Service Systems Advisory Committee, Mental Health Commission of Canada.

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IMPROVING PATIENT CARE FOR MENTAL HEALTH AND ADDICTION SERVICES: A HOSPITAL PERSPECTIVE

Tom Closson*

According to the Canadian Mental Health Association, more than three million Canadians will experience a major episode of depression at some period in their lives.[1] In 2007, Statistics Canada released a research study which showed that half a million Canadian workers experience depression, 80% of whom said that the symptoms interfere with their work.[2] Despite these staggering numbers, depression was found to be a highly treatable illness, with four out of five people who seek help successfully treated.[3]

People living with mental illness have the right to acquire the services and supports they need, and deserve to be treated with the same dignity and respect as others who are struggling to recover from any form of illness. Hospitals have an important and necessary role to play in providing and supporting a broad range of mental health services across the full continuum of care. In Ontario, there are 12 specialty mental health hospitals and over 60 public hospitals that provide inpatient, outpatient, community, day-hospital, and emergency mental health care.

While public awareness is a vital aspect of improving the existing system, other channels of advocacy can also serve this end-goal. The Ontario Hospital Association (OHA) has been advocating on behalf of mental health hospitals for many years, through its Mental Health Working Group (Working Group), and now through the OHA Mental Health and Addiction Provincial Leadership Council (MHA Council).

History of the MHA Council

The MHA Council was established in 2005, emerging out of the Working Group which began meeting in the late 1990s. Prior to the work of the MHA Council, the OHA and the Working Group had diligently advocated on behalf of its members with respect to a number of issues, including:

- The need for a comprehensive, standardized assessment instrument for evaluating the needs of patients receiving mental health services within hospitals. The OHA is a part owner of the Resident Assessment Instrument – Mental Health (RAI-MH) with the Ministry of Health and Long-Term Care (MOHLTC), and the InterRAI which was mandated for all Schedule 1 hospitals[4] on October 1, 2005;

- Supporting the "Central Table" – a group of key decision-makers tasked with moving the divestment of the Provincial Psychiatric Hospitals (PPHs) forward;
- Responses to MOHLTC policy documents such as *Making It Happen*; and
- The response to the summary report of the Provincial Forum of Mental Health Implementation Task Forces in 2002 that developed recommendations for the MOHLTC with respect to PPH restructuring, community reinvestments and the implementation of mental health reforms.

Advocating for Mental Health and Addiction through the MHA Council

The evolution from the Working Group to the MHA Council had many drivers of change, including members' requests for a forum of key decision-makers from the mental health sector that could profile mental health and addiction issues within the OHA and the province. After a formal review of the Working Group by the OHA, a new structure was established which provided for direct reporting to the OHA Board of Directors through the OHA President and Chief Executive Officer (CEO).

The MHA Council, chaired by Dr. Paul Garfinkel, President and CEO at the Centre for Addiction and Mental Health (CAMH), advises the OHA on issues affecting mental health and addiction care in Ontario. All specialty mental health hospitals have a permanent appointment on the MHA Council. As well, the MHA Council includes representatives from acute care hospitals with large mental health units.

As part of its mandate, the MHA Council makes recommendations for the development of health care policy within the field, communicating to the OHA Board, government and other key stakeholders, as appropriate, on important issues impacting the sector. Members also share their concerns and valuable experiences to help each other enhance the delivery of care for the communities they serve.

Future Priorities of the MHA Council

Combating Stigma and Discrimination through a public information video on mental health and addiction

Mental health has recently emerged as a priority for Canadians, detailed in Senator Michael Kirby's report, *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*, which was commissioned by the federal government and released in 2006. To emphasize this need for change, the MHA Council recently developed a video depicting the challenges impacting mental health and addiction in Ontario, to be launched this spring. The MHA Council hopes this, along with other initiatives, will serve to drive policy change and funding enhancements to reduce stigma and discrimination, and improve access to both hospital and community-based mental health and addiction services in the province.

The Mental Health Commission

In 2003 and 2005, the OHA made presentations to Senator Kirby and the Standing Committee on Social Affairs, Science and Technology charged with examining the issue of mental health in Canada. The OHA outlined its key mental health and addiction priorities, and championed the need for a national strategy for mental health. The MHA Council was pleased when the federal government announced the establishment of the Canadian Mental Health Commission in March 2007, further to the recommendations from Kirby's final report. The MHA Council is very supportive of this initiative and plans to establish regular dialogue with the Commission.

Advocating for Mental Health and Patient Safety

Through its work, the MHA Council has learned that more needs to be done, both provincially and nationally, to address the issue of mental health and patient safety. The OHA began advocating to national patient safety organizations respecting the need for leadership in this area and, as a result of discussions between the OHA and the Canadian Patient Safety Institute (CPSI), both organizations have agreed to co-sponsor a National Mental Health Patient Safety Roundtable, to be held in the fall of 2008. The roundtable will bring together researchers, mental health providers, managers and educators from across the country to explore and address the need for new knowledge in the field of mental health and patient safety, culminating in the development of a background paper on the issue.

In order to inform the work of the roundtable and the paper, the OHA and the CPSI have established a Pan-Canadian Advisory Committee to help guide the initiative. The MHA Council is represented on this Advisory Committee and therefore provides ongoing advice and support to the project.

Data Quality Issues: Standardizing Assessment

As indicated earlier, the development of the RAI-MH as a comprehensive standardized assessment instrument for evaluating the needs of patients receiving inpatient mental health services is very important to the OHA and the MHA Council because it allows hospitals to collect data that lead to a better understating of patients' care requirements, clinical outcomes and improvements in quality. The OHA is currently a member of the Joint Policy and Planning Committee's Mental Health Technical Working Group that is tasked with reviewing the System for Classification of In-Patient Psychiatry, which will support the development of a funding formula, or inclusion in an existing funding formula for mental health; these efforts ultimately translate to more accurate funding for hospitals.

In an effort to support the RAI-MH clinical best practices, the OHA with representatives from the MHA Council, annually plan an educational day on the RAI-MH for hospitals to share and learn about these best practices.

Engagement of Community Stakeholders and LHINs

Engagement of community mental health stakeholders is very important to the MHA Council and its advocacy efforts, ensuring that we work collectively toward the same goal of developing an accessible mental health system based on leading practices. The MHA Council has regularly invited representatives from the community sector to speak about key priorities and emerging issues and to examine how we can collaborate towards our common goal.

Similarly, the MHA Council invites Local Health Integration Network (LHIN) representatives who are leads in mental health issues to discuss their areas of concern. Most of the LHINs identified mental health and addiction as a priority in their Integrated Health Services Plans and will begin to make needed changes within their regions to reflect these findings. Thus, it is very important that the MHA Council provide their advice and recommendations to the LHINs.

Mental Health and Addiction – A Vital Part of the Continuum of Care

The MHA Council will continue to move forward with its identified priorities, and tackle new ones as they arise. Because mental health issues can no longer be viewed as an isolated aspect of the health care system and the overall care that is provided to patients, the MHA Council must ensure that it is recognized as a vital component of the continuum of care. Through bodies like the MHA Council within the OHA, the betterment of patient services and the patient experience can be achieved by examining and working through system issues at every level – which ultimately translates to an integrated, accessible continuum of care provided to patients in the most appropriate setting, when and where they need it.

* Tom Closson is President and CEO of the Ontario Hospital Association.

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1 Canadian Mental Health Association. 7 Apr 2008 www.cmha.ca/bins/content_page.asp?cid=3-86-87-91&lang=1.

2 "The Daily - Study: Depression and work impairment." Statistics Canada. 2002. 7 Apr 2008 www.statcan.ca/Daily/English/070112/d070112a.htm.

3 Canadian Mental Health Association. 7 Apr 2008 www.cmha.ca/bins/content_page.asp?cid=3-86-87-91&lang=1.

4 Schedule 1 hospital refers to a designated psychiatric health facility that is required to provide inpatient, outpatient, day care, emergency and consultative and educational services to local agencies unless exempted by the Ministry of Health and Long Term Care and corresponding regulations.

SYSTEMIC ADVOCACY: A CATALYST FOR CHANGE

David Simpson *

Since its inception, the Psychiatric Patient Advocate Office (PPAO) has focused on the need for systemic advocacy to make changes that would have a positive impact on the legal and civil rights of clients and to address issues that would improve the quality of care and life of individuals with an actual or perceived mental illness.

In the spring of 1986, the Honourable Elinor Caplan, Minister of Health, appointed an Evaluation Committee, chaired by Allan Manson, to oversee a comprehensive evaluation of the PPAO. The members of the Evaluation Committee were nominated by the various constituencies which played major roles in the delivery of mental health care in Ontario. Given the experience and expertise of each of the committee members, they were able to play an active role in the project, working collaboratively with the Centre for Research and Education in Human Services, who prepared the final report.[1]

The report conducted by Mr. Manson made two key recommendations with respect to systemic advocacy. Although it found that the PPAO was engaged in systemic advocacy initiatives, the PPAO "needed to more clearly articulate the role of systemic advocacy and non-instructed advocacy within its mandate."[2] The committee also recommended that a "co-coordinator for systemic and policy issues should be added to Head Office staff; the policy co-ordinator needs to have skills in the area of research, policy analysis, and strategies for change."[3] The Evaluation commented that many systemic files were incomplete as many of the cases lacked the documentation necessary to evaluate the effectiveness of the intervention by the Patient Advocate or Head Office staff; instead, PPAO staff relied on the corporate or organizational memory. It also concluded that "several systemic issues have been 'lost' because of poor recording, inadequate documentation and poor co-ordination."[4]

These findings forced the PPAO to realize that things needed to be done differently with respect to the identification and management of systemic advocacy initiatives in order to produce systems level change.

Defining Systemic Advocacy

Systemic advocacy focuses on issues that affect a broad segment of a particular population. A systemic advocacy issue always affects a group of people; they are not individual problems, although they may start out that way. Frequently, they relate to systems-level issues, policies, practices or procedures. Systemic advocacy issues usually require study, analysis, research, administrative changes or legislative remedies aimed at reducing or preventing barriers and ensuring equitable access and treatment of a group of people.

For the PPAO, the goal of systemic advocacy is to promote changes that support the legal rights, social and therapeutic entitlements of clients while addressing power inequities inherent to the mental health system. The PPAO addresses issues that arise locally, regionally or provincially in hopes of bringing about positive and lasting change to the mental health sector in Ontario.

The PPAO believes that systemic advocacy includes such things as: writing letters to the editor; writing academic articles; responding to media inquiries; being on hospital and community-based committees as *ex-officio* members; applying for intervener status in court and tribunal cases where patients' rights are impacted; preparing position papers; and appearing before legislative committees at both the provincial and federal levels. Each of these are key components of a successful systemic advocacy strategy that impacts "how" mental health services are accessed, the rights of vulnerable people protected and promoted, and how the system is encouraged to move forward in a progressive and responsible way, in keeping with client centred best practices that support wellness and recovery.

Influencing and Changing the System

Rights promotion is a process that often requires action on a variety of levels within health and social service systems of care, treatment and support, the courts and government in order to effect change. Systemic advocacy requires diligence and perseverance over a long period, as lasting progress seldom happens overnight. Promoting rights through systemic advocacy is about catalyzing social change – slowly and incrementally raising awareness, reducing barriers to accessing and realizing existing rights and justice, eliminating discrimination and enshrining recognized standards of protection for individuals with mental illness in the law.

Systemic advocacy is intended to break down barriers, change the structure of service delivery within mental health facilities, address quality of care and life issues, reform the law, change policies and procedures and foster collaborative work with community partners. For the PPAO, systemic advocacy is about protecting and promoting the rights of individuals with mental illness.

The Evolution of Systemic Advocacy

Over the years, there has been an evolution in the way that systemic advocacy initiatives are viewed and conducted by the PPAO.

In the early days, the PPAO had great success with its systemic advocacy agenda. Some of early issues resolved, just to name a few, included: ensuring patients working in hospital based work programs received workers compensation benefits if injured on the job; the abolishment of the old "pyjamas" policy that saw the withholding of clothes for punishment and control of patients; the development of patient councils in the provincial psychiatric hospitals; and ensuring that individuals had the right to vote in provincial and federal elections. Each of these issues was important to how patients and their rights were viewed by the system.

Another example of the evolution of "how" the PPAO conducts systemic advocacy involves advocating for an increase in the Personal Needs Allowance. The PPAO led a web-based systemic advocacy initiative in 2002 in order to create awareness of the need for an increase in the Personal Needs Allowance that clients receive while an inpatient in a mental health facility. Numerous clients told the PPAO that the $112.00 per month they received at the time was creating a financial hardship, as the amount was inadequate to purchase the necessities of life. The PPAO decided to engage the clients in their advocacy efforts. A form letter was posted on its website that enabled and empowered clients, families and other interested parties to print, sign and mail the letter to the Minister of Community and Social Services to request an increase in the Personal Needs Allowance, as well as Ontario Disability Support Program benefits in general. The PPAO also worked with other sectors potentially impacted by this advocacy initiative, including organizations supporting individuals with developmental disabilities and seniors. As a result of this campaign, several hundred letters were signed by clients and their families; eventually, the Personal Needs Allowance was increased by a disappointing 2%. There were also many other groups working to address this issue, and in hind-sight, a strong and effective coalition may have achieved a better and more substantial outcome for our clients. However, this is one of the lessons learned which was later applied to future systemic advocacy work.

In June 2006, the PPAO invited stakeholders to attend about the practice of police services across Ontario to disclose information regarding non-criminal contact with police pursuant to the *Mental Health Act*[5] as part of a police records check. A large group of agencies, organizations and individuals got together to discuss this issue and it became evident that the issue was far larger than any of us had imagined and that it had many different facets, impacting people in different ways. The group collectively decided that a coalition should be formed to speak with one voice. In the months that followed, the Mental Health Police Records Check Coalition was formed. To date, the Coalition has approximately 40 members and is co-chaired by the Canadian Mental Health Association – Ontario, Ontario Association of Patient Councils, Community and Legal Aid Services Programme (CLASP) and PPAO. Advocacy efforts by the Coalition include: writing numerous letters to politicians, organizations and police services; conducting workshops; and giving media interviews. Most recently, the Coalition and its members have developed a response to the Ontario Human Rights Commission draft policy on this very issue of police record checks.

There is recognition of the benefits of systemic advocacy but front-line staff require supports and tools to assist them in their thinking about systemic advocacy. Forms such as the "Patient Death Review Form" were used to collect information about the circumstances surrounding patient deaths in mental health facilities in Ontario. This information was later be used by the PPAO when it applied for intervener status before the Human Rights Tribunal of Ontario in a case regarding mandatory inquests for patients when they die in a mental health facilities.[6]

Most recently, the PPAO has designed a systemic advocacy database that will allow on-line documentation of systemic advocacy initiatives. Patient Advocates and PPAO management will be able to search the database, using keywords, to see if other Advocates are working on the same or similar issues. This cross-pollination will allow Advocates to collaborate on regional and provincial systemic advocacy issues and to more effectively and efficiently manage their systemic advocacy files as they progress towards resolution.

From these few examples, it is evident that the PPAO has gone through an evolutionary process with respect to systemic advocacy, although there is still much to be done. Systemic advocacy has and will continue to play a major role in shaping the system, challenging barriers to access and inclusion and in ensuring that the rights of vulnerable populations are protected and promoted. PPAO staff have developed an expertise in the identification, and resolution of systemic advocacy issues over the past quarter century and their work has brought about significant change within the mental health sector in Ontario.

Shifting From Individual Case Advocacy to Systemic Advocacy

There is recognition by PPAO Patient Advocates that they must shift from doing predominately individual case advocacy to systemic advocacy simply due to the number of requests for service they receive and their limited resources. There is an economy of scale in dealing with issues at the systemic level as change has the potential to impact far more individuals. Systemic advocacy will be the way of the future for the PPAO, as it is viewed as an effective use of resources and there is now a move to partner with others to collaborate with other stakeholders in identifying, resolving and implementing change to the benefit of all Ontarians. Systemic advocacy will be our catalyst for change in the years to come.

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[1] Centre for Research and Education in Research Services, *Advocacy in Psychiatric Hospitals: Evaluation of the Psychiatric Patient Advocate Office* (Queen's Printer of Ontario: 1987).

[2] *Ibid.* at p. 86.

[3] *Ibid.*

[4] *Ibid.* at p. 85.

[5] R.S.O. 1990, c. M.7.

[6] *Braithwaite v. Chief Coroner* (2006), 56 C.H.R.R. 171 (H.R.T.O.), reversed under the name *Ontario (A.G.) v. Ontario (Human Rights Commission)*, [2007] O.J. No. 4978 (Div. Ct.); motions for leave to appeal to the Court of Appeal are pending.

AN INDEPENDENT VOICE FOR CHILDREN AND YOUTH: THE ONTARIO PROVINCIAL ADVOCATE

Agnes Samler*

The Journey to Independence

The Child Advocate position was created in Ontario in 1978 and was the first of its kind in North America. It was designed to address the needs of children who were given labels such as "hard to serve," "untreatable," "incorrigible," or worse. The labels often reflected the frustration of service providers who had exhausted all of their usual approaches and had simply given up.

At that time, the Minister of Community and Social Services, Keith Norton, and his Associate Deputy Minister, George Thomson, both strongly believed that all children were entitled to have the supports they needed and were unwilling to treat any child as "hopeless."

Les Horne was appointed as the first Child Advocate. Deeply committed to children, he had a reputation for finding solutions for "impossible kids." The first years of advocacy in Ontario were focused on individual children, as well as identifying and nurturing the natural advocates for children located across Ontario. With highly supportive leadership from the Ministry and local service providers who were grateful for creative interventions, the concept of independence did not seem particularly relevant.

In 1978, the world was still more than ten years away from the adoption of the United Nations *Convention on the Rights of the Child*[1] and concepts of advocacy and children's rights were still in their infancy. Ontario, as a leader in the field, generously shared its knowledge and experience. As other jurisdictions developed a capacity for child advocacy, some recognized the value of separate legislation to support the work of the Advocate and the issue of independence also began to be debated.

In Ontario, the Advocacy Office continued to report to a Deputy Minister, first within the Ministry of Community and Social Services and later through the Ministry of Children and Youth Services. In 1982, Ontario's *Child and Family Services Act* officially identified the Office of Child and Family Service Advocacy and, under the leadership of Judy Finlay, the Office began to expand its mandate to address more systemic issues.

Gradually, the idea of an independent Advocate gained momentum. It became increasingly difficult for the Advocate to report to a Deputy Minister but review and critique policies and programs that were the responsibility of that same Deputy Minister. Even in the best circumstances, where a Minister and Deputy Minister were supportive to the work of the Advocate, there were still difficult and potentially embarrassing situations which could arise, creating a constant risk of the Advocate being silenced on issues that should be made public. Also, the Advocate was simply one voice among many in the Ministry and was often in competition with other priorities for scarce resources.

One proposed solution was for the Advocate report to another ministry within the Government. While this approach might have reduced some of the inherent conflicts of interest, the public reports released by the Advocate still held the potential to embarrass the government.

On November 20, 1989, the *Convention of the Rights of the Child* was adopted by the United Nations. Article 3 includes the commitment that "the best interests of the child shall be a primary consideration in all judicial and administrative actions concerning children." The *Convention*, ratified by Canada in 1991, also provides assurances in Article 12 that "the child shall be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child."

By the end of the 1990s young people in the care of the state began to speak out about the quality of care they experienced and their need to have a strong Advocate to address their concerns. In 2003, a report called "It's Time to Break the Silence," authored by Matthew Geigen-Miller and sponsored by Defence for Children International-Canada, provided a summary of advocacy functions across Canada and recommended that the Advocate become an independent officer of the Ontario Legislature with a position similar to that of the Ombudsman or Auditor-General.

The Provincial Advocate for Children and Youth Act

In 2006, Bill 165, the *Provincial Advocate for Children and Youth Act,* was introduced and fulfilled the Ontario government's commitment to establish an independent Child and Youth Advocate.

The hearings before the Standing Committee on Justice Policy preceding the passage of the Bill were remarkable in a number of ways. Young people came forward to make presentations to the Committee, describing life as wards of the state. Their stories, often put forward in simple language, were powerful and compelling. They talked about the need for change and their inability to have their voices heard.

Representatives from First Nations also came forward to speak to issues that affected their communities in the Northern Ontario, the lack of meaningful supports and services and the absence of hope in their young people.

The process itself was noteworthy in that all parties were committed to the passage of the Bill. While there were differing views among the political parties, solutions and compromises were made so the Bill could be passed without significant delay. The need to have a strong voice for children was recognized and respected.

In 2007, the *Provincial Advocate for Children and Youth Act*[2] was passed in the Legislature with the support of all parties.

Essential Components for Advocacy

The Ontario experience has helped to define the components that make a strong and effective system of advocacy. These include independence, separate legislation, authority to act, and sufficient resources.

Independence

The Advocate provides an independent voice for children and youth. Appointed by the Lieutenant Governor in Council on the recommendation of an all-party committee, the Advocate reports directly to the Legislature. While there is frequent contact with line Ministries, the Advocate is not responsible to any Ministry. This allows the Advocate to raise issues and to be a powerful catalyst for change both at an individual and systemic level. Each year the Advocate is required to provide a report to the Legislature. This report provides an opportunity to ensure the voices of children are heard and issues involving the rights and needs of children are brought forward to elected officials, including the Ministers responsible for change.

Legislation

The *Provincial Advocate for Children and Youth Act* is a separate statute, not associated with any specific Ministry and clearly supports the independent nature of the position. This approach also allows and encourages the inclusion of principles such as those expressed in the United Nations *Convention on the Rights of the Child* and the need to be an exemplar in the meaningful involvement of youth in all aspects of its work. The legislation also emphasizes the need to provide special attention to children with special needs and First Nations children.

Authority to Act

The new legislation also supports the Advocate by identifying a clear mandate and functions. Some of the functions are specifically outlined including providing advocacy to: children and youth who are seeking or receiving approved services under the *Child and Family Services Act*; to young persons being dealt with under the *Ministry of Correctional Services Act*;[3] and to children who are pupils of provincial schools for the deaf, schools for the blind and schools under Section13 of the *Education Act*.[4] In other cases, terms such as "systemic reviews" or "any other advocacy that is permitted under the regulations or any other Act"[5] serve to broaden the capacity of the Advocate to respond to emerging needs. The Act also provides an extensive list of powers to support the work of the Advocate. The overall effect of the legislation is to enable the Advocate to act with confidence and a clear mandate.

Sufficient Resources

Each year the Officers of the Legislature are required to present a budget to the Board of Internal Economy, a committee established under the *Legislative Assembly Act*.[6] This body reviews and is responsible for approving the budgets. While this process in itself does not guarantee resources, it connects the responsibility for budget approval to the Legislature as a whole. It also avoids the situation where the Advocate is competing for scarce resources within a single Ministry.

What's Next?

While the new legislation provides an excellent framework for the new Office of the Provincial Advocate for Children and Youth, the future work of the independent Office is just beginning. Over 3,500 contacts are made to the Office each year and that number is growing. Some are fairly simple, requiring the provision of information or a minor intervention. Others represent complex needs that are not being met and require multiple contacts at a variety of levels to leverage a solution. Some contacts are from children and youth who are being abused, injured in improper restraints, have food or visits withheld as punishment or who spend time in locked isolation, often in violation of the law. While advocacy is carried out on behalf of individual children, the reports and complaints received also assist the Office in identifying system changes that need to be made.

As children and youth bring issues forward, they sometimes risk consequences for providing this information. The Office must be vigilant in holding service providers accountable for maintaining the safety of those young people.

It is recognized that system change is slow and difficult. The role of the Advocate is to identify the need for change, raise issues, create a climate for change and make recommendations to the legislature, governments, ministers, agencies and service providers. The actual change in policy and practice is developed by those responsible for implementation. The challenge for the

Advocate will be to continue to influence and monitor those changes.

As stated previously, the new legislation also calls for the involvement of youth in all aspects of the work of the Office. Young people are already actively involved in the work of the Office and as we move forward, it will be important to prepare and empower them to expand and enhance their role.

The process of developing an independent voice for children and youth in Ontario has taken considerable commitment and persistence but has been well worth the effort. With the cornerstone of independence firmly in place, the Office of the Provincial Advocate for Children and Youth will continue to evolve to meet the changing needs of the children, youth, families and communities of Ontario.

[*] Agnes Samler is the first independent Provincial Advocate, Office of the Provincial Advocate for Children and Youth, Ontario.

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[1] 20 November 1989, 1577 U.N.T.S. 3, 28 I.L.M. 1456 (entered into force 2 September 1990).

[2] S.O. 2007, c. 9.

[3] R.S.O. 1990, c. M.22.

[4] R.S.O. 1990, c. E.2.

[5] *Ibid.*, s.15.

[6] R.S.O. 1990, c. L.10.

RISK MANAGEMENT AND ADVOCACY IN MENTAL HEALTH FACILITIES – WORKING TOGETHER TO PROMOTE CHANGE AND THE DEVELOPMENT OF BEST PRACTICES

Margaret Doma[*]

"No institution could be more powerful or more insensitive to the rights of disadvantaged individuals than the hospital."[1]

The above statement describes the background and philosophy of patient advocacy as it pertained to the 1960s when the American model of the patient representative had its genesis. It was further articulated that the development of the patient representative idea was simple - *"to intervene on behalf of patients who were falling through the cracks of a fragmented system and make the system more responsive."*[2]

Philosophically, health care practitioners would argue that they do provide patient-centered and patient-focused healthcare. Operationally, patients and families might disagree; instead, they might suggest that the care they receive is not individualized and the health care system does not always promote their autonomy and dignity. Although most health care practitioners and administrators would agree that the system has come a long way towards being patient-centered, more work is required before patients unanimously agree that all interactions with the health care system are focused on their needs, goals and rights as individuals.

Which came first – patient advocacy or risk management? Are they interrelated? Do effective advocacy processes manage corporate risk or does managing risk translate to patient-focused care?

The Psychiatric Patient Advocate Office defines advocacy as a "process that ensures that the rights of vulnerable people are protected, that their self-defined needs are met and that they are supported to make decisions that affect their lives."[3]

Stock and Lefroy note that:

> In the health care environment, however, risk management extends beyond this limited financial focus to encompass all elements that directly and indirectly affect the safety and well-being of patients.....risk management is thus concerned with patient care....as well as with the general credibility of the institution and the professionals working therein.[4]

Patient relations or complaints management processes are often a component of health care risk management programs.

Although there are various components to effective risk management programs, for the purposes of this article, we shall focus on the opportunities patient advocates and risk managers encounter that assist them in promoting change, meeting challenges and developing best practices with regards to the resolution of client complaints and concerns.

The roles of patient advocates and risk managers should not to be seen as adversarial opponents but as partners. Although these two roles may approach matters from different legal and organizational perspectives, the ultimate goal is to listen to and value the patient's perception of his or her health care experience.

The following case scenario provides an example of a collaborative approach to the resolution of a client's complaint. Mr. D. approached the patient advocate to voice a complaint about the manner in which a staff member had treated him. Mr. D. also directed the patient advocate to contact the hospital risk manager in order to formally file his complaint with the hospital. The specifics of the complaint were then shared with the risk manager. As per the hospital's complaints and compliments policy, the information was forwarded to the unit manager because a review of Mr. D.'s concerns was required. In the course of the investigation, the staff member who was the subject of the complaint was informed of the impact of her behaviour on the patient. The staff member wanted to apologize to the patient, which was facilitated by the unit manager. Mr. D. was satisfied with the resolution of his complaint. He later told the patient advocate and the risk manager that this was the first time that a staff member had apologized, the first time an investigation was conducted and the first time he was informed of the outcome of his concerns. Mr. D. felt involved in the process from the beginning and more importantly, he felt that his concerns had been heard and validated. He noted that the process was respectful of his dignity.

Risk managers and patient advocates working in mental health facilities have the unique opportunity to collaborate on the resolution of patient concerns and complaints. The challenge is to balance the client's rights and needs with those of the organization.

Communication breakdown is often cited as the reason why clients contact either the patient advocate or the risk manager. This reinforces the need for both the patient advocate and the risk manager to ensure that communication between them occurs in a timely fashion and with clear understanding by all parties as to what issues are in question.

In mitigating this risk, the goal for both the patient advocate and the risk manager is to bring the appropriate individuals to the table in a timely fashion. The desired outcome is one in which the client feels heard, valued and respected. It is important, however, to note that not all resolutions will be satisfactory for all parties. When the process is based on these values, then much has been accomplished given that dignity and respect are essential in the establishment of a mutually trusting relationship.

The unique partnership between the patient advocate and the risk manager offers both an opportunity and a challenge to promote change, manage risk and develop best practices that will enhance client-centered care. The question that remains is: Do we embrace this opportunity to cooperate or do we remain in our 'silos' and hide behind our historical practices?

*Margaret Doma is the Risk Manager at St. Joseph's Healthcare Hamilton, Centre for Mountain Health Services.

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1. American Hospital Association, Society for Healthcare Consumer Advocacy. In the Name of the Patient. Chicago: 2002; 3.
2. *Ibid.*
3. Psychiatric Patient Advocate Office, "Advocacy," www.ppao.gov.on.ca/ser-adv.html.
4. R.G. Stock and S. Lefroy. Risk Management: A Practical Framework for Canadian Health Care Facilities. Ottawa: Canadian Hospital Association, 1988; 7.

A LABOUR PERSPECTIVE ON MENTAL HEALTH REFORM

Warren (Smokey) Thomas*

The restructuring of mental health care has failed to live up to its promise to improve the lives of some of Ontario's most vulnerable citizens.

My union represents 5,600 mental health professionals working in hospitals and community agencies. My background is more than 25 years as a registered practical nurse at Kingston Psychiatric Hospital, now Providence Continuing Care Centre - Mental Health Services.

We work in the psychiatric hospitals where beds were closed and treatment programs have been restructured, downsized or eliminated. We work in the acute care hospitals facing on-going restructuring of beds and programs due to budget pressures. We work in the community agencies taking on services and programs that have often been downloaded from the hospitals. We represent thousands more workers in the province's correctional system which has experienced a rise in the number of inmates with mental illness. We represent staff in child treatment and children's mental health agencies where the demand for treatment far outstrips the available programs.

Two horrifying incidents highlight the continuing crisis in mental health care.

Karyn Graham has called for an inquest after her son, Trevor Graham, 26, was shot by police in November after leaving a Kitchener drug store with stolen medication. He was alleged to have a weapon. Trevor and his family had endured 14 years on the haphazard merry-go-round of what passes for treatment for mental illness and drug addiction in this province.[1]

The parents of Trevor Lapierre, charged with the murder of a Kitchener man in December, said they tried unsuccessfully for a year to get their son treatment. Hunter Brown, 74, was killed with an edged weapon while out delivering Christmas cards to his neighbours. Lapierre, 22, and his father were en route to the psychiatric ward at Grand River Hospital when he was arrested for his murder.[2]

The violence behind these two deaths is linked to two decades of misguided provincial policy to shift resources from specialized hospital treatment to community programs.

In 1999, the provincial Health Services Restructuring Commission recommended cutting 1,133 Provincial Psychiatric Hospital (PPH) beds, a dramatic 39% drop from 1995/96 bed figures. The report stated "the proposed hospital bed targets are achievable once the appropriate community services and supports are in place to reduce reliance on institutional care, especially PPHs, and dramatically reduce the need for hospital-based treatment services."[3]

The success of mental health reform depended on community supports being in place before psychiatric hospital beds and programs were closed.

That did not happen.

Nine of the ten PPHs were offloaded to general hospitals, many of which had administrations with little experience in specialized psychiatric care. Hundreds of beds were closed, programs restructured and staffing reduced.

In our 2002 report, *Reality: The Mental Health System Isn't Working*, we reported on the anecdotal experience of our members dealing with the consequences of the restructuring. One of our members observed: "Poor planning and lowered staffing levels mean mentally ill clients are showing up in police custody, on the street or in emergency rooms at local hospitals where staff aren't always trained to deal with them."[4]

Our members' experiences were reflected in the interim findings of a four-year research project into the impact of the province's funding increases to community mental health. The System Enhancement Evaluation Initiative released interim key findings in June, 2007. They included:

- An increase in hospital admissions and visits to hospital emergency rooms during the study period; and
- An increase in police involvement with people with mental illness in regions that were monitored.[5]

The lack of specialized community resources and the impact on psychiatric hospitals, under pressure to discharge patients, was cited in a review of the operations and finances of four former PPHs prepared for the Ontario Ministry of Health and Long-Term Care (MOHLTC). The report reviewed 21 programs at the psychiatric hospitals. Two-thirds of the programs reported difficulties discharging patients to community settings.

The report cited "external systemic issues," including "community programs have limited capacity to absorb the volume/number of patients flowing from in patient services in a timely manner," and "many community resources lack the specialized training and knowledge to support patients in the community setting."[6]

Since 2004, the provincial government has spent an additional $142 million on community programs. Even so, funding for mental health care has not kept pace with the huge increases in health care spending overall. The share of Ontario's health care budget spent on mental health dropped to 3.3% in 2007 from 5.3% in 1998.[7]

More evidence of the crisis in mental health care mounts.

People with serious mental illnesses can wait from four to six months to see a psychiatrist.[8]

One desperate 30-year-old Ontario woman could not find a psychiatrist to treat her outside the hospital for depression no matter how hard she tried, even though this mother of two could not regain custody of her two young children without one. Her children had been taken away in the course of her four hospital stays and psychiatric care was one condition of their return.[9]

At any given time, 7,000 children are waiting an average of six months to get an appointment with a mental health specialist.[10] Wait times of up to a year or more are not uncommon for most people in rural and northern Ontario, as well as Aboriginal communities.

Yet even though there is clearly a crying need for greater resources, there is no requirement for hospitals to fund mental health programs beyond the amounts earmarked by the province.

In its planning document to Ontario hospitals, MOHLTC says hospitals "are not required to supplement mental health programs from their global budgets. As a result, hospitals may reduce mental health programs and expenses to the level of [protected] funding."[11]

No other health services are openly put on the chopping block in the same way as mental health.

What happens to people with mental illness when they're denied timely treatment or are discharged to a community ill-equipped to care for them? Many end up in shelters, jails or on the street.

The link between homelessness and mental illness is well documented with about a third of homeless people in general, and up to three quarters of homeless women specifically, living with a mental illness. In Ontario, some estimate 6,100 people sleep in shelters every night – out of these, 2,013 have a mental illness, and 1,220 have an additional concurrent disorder, or an addiction.[12]

People with a dual diagnosis of a developmental disability and mental illness are drastically underserved in the community. Hospitals are not able to discharge these patients "due to a lack of community resources and these resources do not feel equipped to address the level of care provided for these patients. … In particular, there is a significant lack of appropriate housing." [13]

Compounding the crisis has been the provincial government's closure of provincially-run facilities for individuals with developmental disabilities, many of whom also suffer from a mental illness, adding another complex group into the community care system.

People suffering from a concurrent disorder of an addiction and mental illness, which in some populations, such as those with bipolar mood disorder, can range as high as 50%, face a desperate lack of community programs. And yet, a highly respected concurrent disorder program once run out of the psychiatric hospital in St. Thomas, had its program restructured and beds reduced from 28 to 12 after the psychiatric hospital was taken over by St. Joseph's Health Care, London.[14]

Another pressure point affected by mental health shortages is the lack of specialized long-term care facilities for people with mental illness.

Geriatric psychiatry programs in hospitals cannot discharge patients because "…there are simply not enough appropriate long term care beds that are staffed with the specialized knowledge and skills to care for this patient population."[15]

Even so, a growing number of people with mental illness, dementia or Alzheimer's end up in long-term care homes, sometimes with disastrous consequences.

In 2004, a 96-year-old resident of a prominent Ontario nursing home was beaten to death by another resident. The 78-year-old man, who had wandered into the woman's room, had a history of mental illness and violent actions, including previous arrests for assaults.[16]

It has been estimated the rate of mental disorders among nursing home residents ranges from 65 to 91%.[17] Has this anything to do with the fact that in Ontario between 2003 and 2006 the number of violent incidents among nursing home residents has more than tripled to 1,416 cases?[18]

Another dumping ground for individuals with a mental illness is our jails. The number of people coming in contact with the law is increasing by 10% a year, mostly for non-violent violet offenses.[19] Often homeless, or with no fixed address or community ties, they end up remanded in custody.

But social status does not make one immune to "treatment via lockup" as shocked Canadians learned when it was reported that talented 53-year-old comic Tony Rosato – of *SCTV* and *Saturday Night Live* fame – had been kept in maximum security detention on remand for two years for criminally harassing his wife, even though she clearly wanted him to get psychiatric help for his growing delusions.[20]

It is been estimated the proportion of Ontario inmates with a mental illness ranges from 15 to 20%[21] and we know in the federal system, such cases doubled from 1995 to 2005.[22] Two out of three juveniles in the justice system have a serious mental health issue.[23] It is interesting to note that in 2007, the per diem cost of keeping an adult in jail is about $150 compared to $400 to $800 for a hospital bed.[24]

It is no wonder that in the wake of restructuring, it has become difficult to attract and keep workers in mental health care, particularly at a time when there are labour shortages in many sectors of health care in the province.[25]

Numerous government reports have referenced the problem, but few solutions seem forthcoming.[26]

A MOHLTC report on downloading hospital services to the community noted, "Consistency in relationship between the client and the service providers is vital." When staff feel anxious about their job security, "client care has the potential to become inadvertently compromised. The objectives are to preserve existing (staff) capacity and to build new capacity." [27]

Community mental health often pays less. If we want to keep a skilled and experienced workforce and attract new workers to mental health care, wages, benefits, and training opportunities have to be substantially improved.

Recruitment and retention is also an issue in hospitals. The report on four psychiatric hospitals for MOHLTC cites an aging workforce, difficulties recruiting sufficiently trained staff, a shortage of psychiatrists and registered nurses and inappropriate staff mixes as major problems.[28]

At our 2007 symposium, *Action Now for Mental Health*, a gathering of activists, policy-makers, academics and health care professionals, OPSEU presented these five priorities for change:

- eliminating cuts to hospital mental health programs;
- accessing more forensic beds and court diversion programs;

- making housing a right;
- establishing income security for individuals with a mental illness; and
- addressing wage inequities between hospital and community mental health workers.[29]

As long as services are fragmented, not grounded in the social determinants of health, and do not retain a highly-skilled and experienced workforce, reform initiatives in mental health care are doomed to fail.

Participants at the symposium urged greater co-operation and action between the different provincial government ministries that play a role in improving the health care and social supports that people with mental illness so urgently require.

The union recommends a government roundtable to consider expanding the Psychiatric Patient Advocate Office's (PPAO) authority and mandate within general hospitals and community services serving people with mental illness. Currently, the PPAO is a designated rights adviser with respect to the majority of general hospitals in Ontario, as well as community agencies serving those on community treatment orders.

The PPAO is only allowed to fulfill its independent advocate role in designated psychiatric hospitals. As psychiatric hospital inpatient programs and beds are cut and individuals with mental illnesses move into general hospitals and the community, it only makes sense that the PPAO's independent advocacy role expand there as well.

My union has a 30-year history of drawing attention to the failures of the system to provide treatment, care and support to those who need it.

Those of us on the frontlines urge the Ontario government to respond to the crisis facing the most marginalized members of our community and make mental health a provincial priority. We should all stand for no less.

*Warren (Smokey) Thomas is President of the Ontario Public Service Employees Union (OPSEU).

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ETHICAL PERSPECTIVES IN PROVIDING MENTAL HEALTH CARE FOR A POPULATION OF INCREASINGLY DIVERSE LANGUAGES AND CULTURES

Steve Abdool* and Joseph Chandrakanthan**

Consider the following situation: A 70 year-old lady, living at home with her husband, is diagnosed by her family doctor with clinical depression with psychotic features. She and her husband migrated to Canada from the former Yugoslavia about 15 years earlier. They have two children, who are both married and reside in another city. The couple refuses consent to share her health information with their children. The patient was more recently diagnosed with cancer of the cervix with possible metastases. The patient adamantly refuses further investigations or treatments for both her psychiatric condition and her malignancy. She is apparently showing signs of hypervigilance and paranoia – not trusting anyone, even to the point of breaking up her food products into tiny bits to check for hidden drugs. Her only source of fluids is water, which she insists on pouring herself from the water tap. The patient's husband is very protective of his wife and believes that everyone else should respect her wishes. He threatens to refuse to allow the family doctor or other community care workers to enter their home should they insist on forcing his wife to be treated. Both the patient and her husband have only a basic understanding of English. How should we approach this patient's holistic care?

Canada, and more specifically the city of Toronto, has one of the world's most diverse populations with respect to races, cultures, ethnicities, languages, and other such expressions of identity. Varying understandings of the relationship between one's self and that of a larger collection of peoples, ideas, beliefs, memories, and places, have forced health care professionals and administrators to re-examine the implications of this upon the processes in which those with mental illnesses access, receive, and/or refuse treatments.

In the latter half of the twentieth century, diversification of the Canadian population became a prominent and well-recognized reality of a Canadian identity itself. With the removal of "racial quotas" for immigrant applicants, the recognition of Canada's obligations to refugees overseas, and official national policies of liberal multiculturalism, immigrants became, and continue to be, a prominent and visible influence upon the diversification of Canadian society.

Increasingly, as Canada attempts to fulfil its obligations to refugees as part of its international obligations, many of those arriving in Canada come with experiences of state oppression, starvation, famine, war, violence, and genocide. Many times, Canada has become a home out of necessity, as refugees are accepted based on the degrees of difficulty and persecution they faced as opposed to the "necessary skills" and "independent support systems" in place as part of the process of applying as an immigrant.

Consequently, the influx of immigrants into Canada has brought about a diversification of not only cultural, ethnic, and racial identities, but also a diversification of experiences and traumas compounded by socio-economic and often communal difficulties. This is further complicated by the multi-generational diversification of identities that have evolved within Canada from an "immigration experience" combined with contemporary, collective experiences within Canada, providing new means and understandings of self-identity in highly rich and complex forms. Emerging from this are very complicated configurations of both self and community in terms of identity. It is from the unresolved scars and traumas of conflicts, the absence of traditional coping strategies subsequently lost through traumatic upheavals, and the disintegration of broader family and social ties, that the process of immigration further complicates this situation.

Socio-cultural sources of stigma and labelling associated with 'mental illness' influence patients', families', health care professionals' and society's perception and treatment decisions. This poses challenges regarding illness identification, care and recovery especially when there is an aggregation of diverse cultures as in the Canadian society. Such obstacles may include: a deep mistrust of the institutions/experts; beliefs in the unreliability of diagnosis; differing norms and understanding of mental illness in general; significant poverty/socio-economic dimensions to health and coping; uncertain or lacking understanding of mechanisms and support systems already in place; fear of further persecution and/or stigmatization; language/gendered/cultural/normative differences creating perceived and possibly real barriers; real or imagined ideas of a lack of accommodation; the inability to identify with mental health workers due to a lack of understanding on one or both sides; preconceived notions of the expert and the powers/implications/fears of a tyranny of experts; and a lack of knowledge on self-advocacy and rights, with far-reaching implications and potential fears for both self and family.

Governments and health care organizations need to actively support advocacy initiatives, for instance, to develop language skills (especially for new immigrants) and to better appreciate the concepts of legal and civil rights. Appropriate training will assist in elevating these individuals to more secure socio-economic positions in this capitalist society. Self-help groups are crucial in this empowerment process. It is often comprised of individuals with similar experiences, with and without a common cultural orientation, which may serve to explore, appreciate and manage biases, prejudices and discrimination. Increasing consumers' participation in service planning and delivery at all levels is another vital step in this process.

There is a great need for public education in meaningful and compelling ways in an attempt to significantly reduce – and to eventually eradicate – myths relating to both people from diverse culture and mental illness itself and, in so doing, to more honestly convey the truths about mental illness and those unfortunate enough to suffer from it, as well as the plight of their families. Much greater efforts should be placed on portraying mental illness more accurately in all media – newspapers, radio and television – as a matter of social responsibility and ethical journalism. Advocacy groups should vigorously protest labelling, stigmatizing and stereotyping of people with mental illness as these individuals are more likely to be victims (rather than perpetrators) of crime and aggression according to a variety of studies.

Every effort should be made to personalize people with mental illness – they are real people with real lives and real suffering too! Their needs are much the same as most others; that is, they want a place to call home, to feel safe, perhaps to have a family and to be treated with dignity and respect. As part of changing the public's attitudes and behaviours, we should learn to not only tolerate and respect, but to actually also celebrate, differences of all kinds, including cultural, racial, sexual, and religious diversity. It would be prudent to initiate strategies to change public attitude early on, say at schools and other public institutions.

The integration of education relating to culture, stigma and labelling in the educational curriculum of health care professionals needs further expansion to enable them to become more culturally sensitive and competent. This would also serve to allow them to become more aware of, and to disallow, transference and counter-transference issues in dealing with clients and their families. An effective method to become adept in identifying and averting transference and counter-transference issues in the clinical encounter would be to engage in self-exploration of personal values and beliefs in a safe environment, such as at experiential workshops.

Furthermore, utilizing the collective wisdom of the interdisciplinary team (including the client of course, as appropriate), whenever such resources are available, would promote consensually driven or a more democratic (rather than autocratic) decision-making process. Conformity to professional standards of best practice and incorporating sound ethical reflection processes would be invaluable to arriving at decisions that are based on the client's own values, beliefs and best interests, rather than on assumptions, generalizations and other inadvertent prejudices.

It is crucial to assist clients to regain a sense of dignity and self-worth. This may be accomplished in part by counselling and supporting them to replace negative with positive self-talk. To further empower them to gain a better understanding of, and insights into, their illness and experiences, it would be important to provide them with education about mental illness and its impact on individuals and families, all in a language that they understand and appreciate. Given the reservations and fears that many clients have about sharing information regarding their experiences and illness, it would be essential to assist clients to decide when and how it is best to disclose illness and, indeed, for their health care providers to actively support in this process whenever possible.

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UNFINISHED BUSINESS
MENTAL HEALTH POLICY IN ONTARIO SINCE 1983

Gail Czukar*

Mental health policy reform in Ontario can be described (perhaps unfairly) in two words: incremental and gradual. Each wave has added some new elements to the picture, but none of the changes could be said to have been "radical". Perhaps this is a good thing for the system and for people with mental illness. Change can take shape gradually, we can learn from our experience, and people can benefit from this. However, some would say that entrenched political, professional and advocacy interests in maintaining the status quo have prevented people with serious mental illness and addictions from having the very best thinking and services in Ontario. And that what "they" REALLY need is still only sporadically available in many communities in Ontario.

I feel honoured to have been asked to present a brief overview of mental health policy in Ontario over the past 25 years, some personal reflections and thoughts about the future. No doubt you will draw your own conclusions and have your own views about the pace of policy change and its effects on people who may have mental illness in Ontario.

Mental Health Policy in 1983

Twenty-five years ago, the mental health system in Ontario consisted of ten Provincial Psychiatric Hospitals, several general hospital psychiatric units, and a good representation of community-based services. The provincial psychiatric hospitals were slowly but steadily downsizing. The consumer movement and family organizations were becoming established.

There was no specific plan or articulated policy for mental health care. A 1979 report from the Ontario Health Council, *Agenda for Action*, had addressed some aspects of such a policy. A plan for change was developed in 1983 with the Heseltine report, *Towards a Blueprint for Change: A Mental Health Policy and Program Perspective* – the first government framework for mental health policy. It emphasized a continuum of services, and stated a clear preference for rebalancing spending from institutions to community programs. At the time, well over 80% of the mental health budget was spent in hospitals.

Two events in the mid-eighties fundamentally altered mental health policy in Ontario. In 1985, David Peterson's Liberal government was formed, ending the 42-year Conservative reign. Since that time, Ontario voters have exercised their franchise to make frequent changes in their governments. With each change of government came new mental health policy and revisions to the mental health system. Fortunately, Ontario was blessed with several ministers of health who had a passion for mental health issues. Without this personal interest, mental health might not have achieved even the incremental gains we have seen, for it has always been the lowest priority in the health budget.

Effect of the *Charter of Rights and Freedoms*

Also in 1985, the equality rights section of the *Canadian Charter of Rights and Freedoms*[1] came into effect. These provisions precipitated a flurry of litigation and legislative reform in the late 1980s and early 1990s, centered on protection of due process and substantive rights to liberty on the grounds of mental disability. In Ontario, people who were involuntarily hospitalized due to their mental disorder acquired greater rights to hearings and appeals. The criteria for such detention were narrowed to *imminent and serious bodily harm* and *inability to care for oneself*. Consent to treatment and substitute decision-making reforms increased the autonomy of people who might become, at times, incapable of making their own decisions. A person found incapable of making those decisions could designate a substitute decision maker, and could compel that substitute to follow their wishes and preferences.

These legal changes made it more difficult for hospitals to hold and treat people purely for reasons of safety or potential benefit from care and treatment. The changes also increased the pressure on the government to create non-hospital services that people were more likely to choose, such as alternative crisis services and supportive housing. One of the most significant of these changes occurred at the federal level with the 1992 amendments to the mental disorder provisions of the *Criminal Code of Canada*.[2] These changes made it less onerous for people with mental illness who became involved in the criminal justice system to get access to assessments and services, and made the new *not criminally responsible* designation significantly more attractive than the pre-existing *not guilty by reason of insanity*. This has led to unprecedented growth in the forensic mental health system and this trend continues unabated.

1988: *Building Community Support*

In 1988, *Building Community Support for People*, otherwise known as the Graham Report, broadened the scope of the mental health system. It called for district health councils and hospitals to develop plans for more comprehensive, integrated local service systems that would provide 11 essential functions, including peer support and advocacy. The health minister of the day promised to introduce mental health services legislation that would embody these principles and functions, as well as a comprehensive system planning framework. Alas, the election was lost before this dream could come to fruition.

Nevertheless, the implementation process that followed the Graham Report was responsible for launching a new phase of consumer and family involvement in the planning, development and evaluation of mental health services. The Consumer-Survivor Development Initiative was launched. Now called simply *consumer survivor initiatives*, or CSIs, these unique programs are run by consumers and they offer peer support of many different kinds to people with mental illness. Consumer-run businesses, which also started up at the end of the 1980s, are another great example of people with mental illness asserting their own path to health.

1993: *Putting People First*

These developments were reinforced in the 1993 report *Putting People First*. It articulated a 10-year plan specifically aimed at shifting the balance more towards the community, from a system in which 60% of the resources were in the hospital sector to a system where 60% would be in the community. Although the goal of shifting the balance had been referred to in the Heseltine and Graham Reports, no targets had been set, nor was there a clear strategy to get there.

Putting People First was grounded in a health perspective and was the first mental health reform document to clearly describe the importance of determinants of health in achieving mental health. However the strategies did not explicitly include the determinants. This policy document also established the priority for service to seriously mentally ill people in the adult community mental health program of the Ministry of Health. This was important because, up to that point, the community mental health programs had often been seen as being suitable only for people who required some support and aftercare following hospital treatment. Consequently, clients were often seen as "not ready" for the community and some community programs were very reluctant to accept seriously ill people.

In the period from 1993-96, district health councils developed system plans, and paid more explicit attention to access and coordination issues. The lessons of past deinstitutionalization, which took place in the absence of adequate community supports, were frequently noted. Linkages, authorities, lead agencies, and best practices in service system design were emphasized, as well as investments in new services.

1999: *Making it Happen*

Who knows what might have happened if the 1995 election had not resulted in yet another change of government? But a new government was formed, and so a shift in policy was called for. Mental health reform became inextricably linked to major changes in the general health system – most notably, the work of the Health Services Restructuring Commission. In 1996, the Commission recommended the establishment of mental health authorities, and set the stage for divestment of the provincial psychiatric hospitals through its orders. Divestment began in 1998 with the transfer of the Queen Street Mental Health Centre to the Centre for Addiction and Mental Health. In 2008, only the Mental Health Centre at Penetanguishene, which includes the provincial maximum secure facility, remains under government operation, and plans for its divestment are under way.

A minister in this new government also had a passion for mental health. As a result the government continued to make strategic funding investments in the mental health system (or "reinvestments" as they were labelled). It also issued *Making It Happen* in 1999, which was a renewal and implementation plan for the previous policy. The call for a comprehensive mental health services statute was renewed, but once again plans for ambitious legislative change were thwarted by the election cycle. In its place, a legislative solution was simplified to include only community treatment orders. While this was a highly controversial reform that divided the sector, it did precipitate additional funding for case management and other supportive services that would help bridge the hospital-community gap in more tangible ways.

Mental Health Implementation Task Forces

About the same time, the government established nine Mental Health Implementation Task Forces to support the planning for divestment of the provincial psychiatric hospitals, and the establishment of local service systems. These task forces reported to government in 2002, and most of them recommended a structural solution to speed progress toward balancing the system. They called for mental health authorities with control of a single funding envelope for all mental health service funding; this would allow for faster reallocation of resources from hospitals to community services. These task forces also introduced the recovery philosophy formally into the mental health policy discussion. However, there was an election before the task force recommendations could be fully implemented.

2003: "The Transformation Agenda"

In 2003 a new government launched another wave of major health reform, arguably more major than any other in the past 25 years. The transformation agenda was launched, including formation of the Local Health Integration Networks and transition to a "stewardship" role for the Ministry. This Minister of Health and Long-Term Care also had a passion for community mental health, and made major investments in community mental health services, both increasing the general capacity of the system and targeting specific strategic initiatives such as criminal justice, crisis management and early intervention. In fact, this is the largest single investment made by any government in the community mental health system in such a concentrated period of time.

The recommendations of the implementation task forces have been (marginally) realized. LHINs are not yet fully formed authorities, as envisioned by the task forces, but they have the tools to achieve the balance envisioned. If these powers are used, it remains to be seen to what extent this will achieve gains in access and service coordination, and how much of an improvement this will make to the quality of life for clients and their family members.

The Present Day

And so we come to 2008. What do we have to show for all this system reform and policy activity? I'll start with the good news: If you told me in 1983 that mental health programs were increasingly located in community settings, and that community programs were demonstrating significant success in meeting the needs of those with serious mental illness, I would have been happy. If you had told me that both consumers and families were better organized, with far greater capacity to systematically advocate on their behalf, I would have been happy. If you had told me that psychiatric hospitals were recognizing the need to work seamlessly with community providers, I would have been happy. And if you told me that the staff and patients at the (then) Queen Street Mental Health Centre bought their coffee at a business run by and for patients and former patients, I would have been surprised, and delighted.

But I desperately hope that things get better in the next 25 years because there is so much work left to do. Despite the significant community investments of the past four years, the portion of the health budget dedicated to mental health has decreased, rather than increased, from about 5% to 3%.[3] In other countries such as the United Kingdom and New Zealand, mental health comprises 10% or more of the health budget. This is a target we should aim for – it would better reflect the burden of disease that mental health problems represent.[4]

Twenty-five years from now

I have a vision for 2033, which I hope I live to see. A person who is feeling anxious and depressed and isn't getting to work some days on account of having a hangover goes to her family doctor. The doctor asks a few gentle probing questions and suggests she see another member of the Family Health Team (FHT) who can help her identify some specific actions and options that might be helpful to her in dealing with the depression, stilling the anxieties, and reducing the drinking. This might include a mindfulness-based stress reduction program at the local hospital, a 12-step program to deal with the alcohol addiction, and an exercise program. as well as some sessions with a psychotherapist. The FHT member who might be a nurse, a social worker, a community mental health worker, occupational therapist, or have some other professional designation) helps the woman decide what program will suit her and makes the connections to get it rolling, then follows up weekly or as needed to see how the woman feels it's going.

Another person who has been monitored by the same FHT for some years has schizophrenia. He has been stable for a long time but recently his mother died, and he has lost some ground. He has started smoking weed again, goes off his schizophrenia medication and, within a few weeks, has been picked up by police for being disruptive and threatening in the street near his apartment. The FHT worker assigned to him comes to the jail and makes a plan with the court support workers and the Crown for the young man to re-enter hospital until he is stabilized again. She also contacts the housing support provider to ensure his apartment is not rented to someone else. The plan is accepted by the Crown, and the charges are withdrawn. The hospital intake worker, the housing support worker, and the FHT member agree on a communication plan to ensure that when the young man comes out of hospital, appropriate follow up occurs.

In that world, I hope that every person with a mental health problem will have access to the benefits and rights of full citizenship, including decent and reliable housing, fulfilling employment, and social engagement. I hope they will experience no discrimination from the health care or social service system when they seek help for their conditions, or need income or other kinds of social assistance to achieve stability again.

Let's Celebrate Progress!

I am delighted to join in the celebration of what has been accomplished in mental health policy over the past twenty-five years. We have made significant changes to a system with many deeply entrenched interests. People with mental illness and their family members are much more involved and visible in the world today, and mental health issues are not quite the taboo topics they once were. This has been accomplished through the hard work of many dedicated and caring people. But this celebration is tempered with the realization that the best mental health policy documents depend on political will, well-spent resources commensurate to the problem, and consistently respectful treatment by professionals in the system to allow consumers and families to be the best they can be. This is a task not yet complete and continues to be a worthy aspiration.

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1 Part I of the *Constitution Act, 1982,* being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

2 R.S., 1985, c. C-46.

3 Schizophrenia Society of Ontario, Provincial Election Brief, Toronto, 2007.

4 Lurie, S., Comparative Mental Health Policy, Presentation, Whitby Ontario, November, 2007.

[*] Gail Czukar has been involved with mental health policy and law since the mid-1970s, and is currently an Executive Vice-President at the Centre for Addiction and Mental Health in Toronto.

THE MENTAL HEALTH COMMISSION OF CANADA – ENTHUSIASTIC BEGINNING/EXCITING FUTURE

Glenn R. Thompson[*]

Just as the Psychiatric Patient Advocate Office needs broad public support for its important work to be fully successful, so does the Mental Health Commission of Canada (Commission). The Commission needs enthusiastic support from all sectors and regions in Canada if it is to succeed in its role as a catalyst for dramatic change in our mental health system. We believe the Commission's work can assist everyone who wants to place mental health higher on our public policy and funding agenda across Canada.

Since 2001, the government in the United Kingdom has spent over £ 2 billion on mental health services (three times more than promised!). Australian states have committed to give $ 1.9 billion to mental health services over the next five years and that amount will be matched by their national government. In New Zealand, I am told the government plans to devote 10% of its health expenditures to mental health and addictions programs, up from 8%.

During several years as Co-Chair of the Senate Committee that produced the national mental health report entitled *Out of the Shadows At Last*, Michael Kirby became very aware of the many areas where Canada does a poor job in caring for persons living with a serious mental illness.[1] *Out of the Shadows At Last* is the first comprehensive, national mental health study in Canada.

One of the report's recommendations was the creation of a mental health commission. The federal government approved the creation of the Commission in its March 2007 budget.

Readers may find it useful if I review some information about the origins of and early plans for the Commission. In this article, I will list: important underlying principles; what we will do; what we will not do; how we are structured; and our key priorities, particularly the national strategy.

Underlying Principles of the Commission

- The Commission is a "national," not a "federal," body;
- All provinces and territories are on side with Quebec in a bilateral relationship;
- There is enormous support across all stakeholder communities for the Commission;
- There is broad agreement that recovery must be at the centre of a transformed mental health system;
- There is an emerging national consensus that coordinated community-based services, well integrated with hospital care, are key to mental health system reform; and
- Tremendous economic incentives exist to address mental health needs, especially in the corporate sector.

What the Commission Will Do

- Be a national focal point for mental health issues;
- Be a catalyst for the reform of mental health service delivery;
- Provide information to government, providers and

the public; and

- Enable collaboration and exchange within and across sectors.

What the Commission will NOT Do

- Provide any services itself (except for the management of the national anti-stigma campaign and the Knowledge Exchange Centre);
- Monitor government performance or be a lobbyist; and
- Fund ongoing services (except to ensure that money from an eventual Mental Health Transition Fund is spent on initiatives that emphasize community-oriented mental health services and system integration); instead, we will encourage and facilitate the funding and development of demonstration well researched projects.

Key Tasks of the Commission

- Establish a ten-year anti-stigma and anti-discrimination program;
- Set up a Knowledge Exchange Centre; and
- Develop a national mental strategy for Canada.

National Strategy

A. Steps Towards A National Strategy

Dr. Howard Chodos, National Strategy Director, is leading the development of the National Mental Health Strategy. Our plan is to have the report completed in three years. Canada is the only G-8 nation without such a strategy. The steps in the development of the strategy are as follows:

- Agree on process;
- Solicit input;
- Gather information/data;
- Define issues;
- Debate possible solutions; and
- Propose courses of action.

B. Success Factors For a National Strategy

- Every stakeholder group must contribute to a national strategy, especially persons living with a mental illness and their families and support persons, but also the full range of service deliverers, the media, employers, unions, schools and faith-based communities;
- Devise a pragmatic national strategy that considers financial costs and available resources.

The Structure of the Commission

The Commission consists of three branches:

1. Eight advisory committees to lead in the examination of what can be done in their respective areas of study to form part of a national movement for change and a national strategy.
    a. Aboriginal, Inuit & Métis Advisory Committee;
    b. Seniors' Advisory Committee;
    c. Child and Youth Advisory Committee;
    d. Workforce Advisory Committee;
    e. Family and Caregivers Advisory Committee;
    f. Mental Health Service Systems Advisory Committee;
    g. Science Advisory Committee; and
    h. Mental Health and the Law Advisory Committee.
2. The Board of Directors is comprised of the chair, seven governmental directors and 11 non-governmental directors; and
3. The Executive Director is in charge of operations to whom the staff Directors report. There are Directors of Policy and Research, Information Services, Finance and Administration and National Strategy.

Progress Report

In this brief article, I also want to provide a progress report and to outline the Commission's plans for the future.

The Commission has assembled an excellent and widely representative Board of Directors, and extremely capable "specialist" chairs of the Advisory Committees. Each of the Committees, like the Board of Directors, has members who are persons living with a mental illness.

Our first Board meeting was held in Calgary in September 2007 and since that time our Advisory Committees have developed and refined their work plans.

After extensive study of international programs, we are about to implement a ten-year action plan with regard to anti-stigma, based on the practices and successes in other countries.

We currently have an expert steering committee advising on a strategic business plan for the Knowledge Exchange Centre. Our consultants have spent several months developing a very thorough plan to meet what is recognized as a great need in the mental health field.

Calgary is the location of the Commission's head office. The Calgary office space officially opened in mid-April and we have hired several employees. Our office in Ottawa will continue with its small staff team.

Michael Kirby had our Board and Committee chairs, all

26 of them, spend the first three hours of their first Board meeting answering the question: "What would you like to see accomplished in the first three years of the Commission's work?"

Several Board members and Advisory Committee Chairs said it was three of the best hours they have spent in this field because the passion, determination and diversity of views was inspiring.

How Can those in the Field of Social Justice Best Work with the Commission?

Mental illness is one of society's most prevalent, persistent and costly diseases. It is very much on the radar screen of employers, school leaders, insurance companies and many others. The public and the media are more engaged and ready to support and report on these changes than they have ever been We are at the threshold of the type of movement for change that we have witnessed for cancer over the past 50 years and, more recently, in the HIV/AIDS area.

In order to be successful, we need high level interest from employees, their unions, their employers, academic institutions, social and recreational facilities, our religious institutions and, of course, from direct service workers and groups representing persons living with a mental illness and their families and caregivers. They need to speak out and take action in their areas of responsibility.

Conclusion

It is our priority at the Commission to ensure that the focus of all of our Board, Advisory Committee and staff activities are centered on persons living with a mental illness, as well as that person's family and other key support persons. Our work covers all age groups and all of the circumstances in which these persons and their families find themselves.

We will lift evidence-informed and promising practices into wider awareness. We will be involved in public education and anti-discrimination activity via the anti-stigma program and, of course, we will work on the national strategy to develop the best way to weave together all of those many parts of the mental health and substance abuse fields to create a national blueprint for the most accessible and coherent system possible.

It's an opportunity seldom presented in any country.

I'm sure you will do your part to help us.

* Glenn R. Thompson, MSW, RSW is the former interim president and CEO of the Mental Health Commission of Canada.

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[1] M.J.L. Kirby and W.J. Keon. Out of the shadows at last: transforming mental health, mental illness and addiction services in Canada. Ottawa: Standing Senate Committee on Social Affairs, Science and Technology; 2006. Available: www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/rep-e/rep02may06-e.htm.

RIGHTS ADVICE – THE EVOLUTION

Linda Carey*

The Psychiatric Patient Advocate Office has been providing rights advice under the *Mental Health Act*[1] (*MHA*) and its regulations since January 1986. Rights advice is a process by which patients in psychiatric facilities and individuals in the community who are being considered for community treatment orders (CTOs) are informed of their rights when their legal status has changed. If the individual is incapable of making a decision regarding a community treatment plan (a part of the community treatment order), the individual's substitute decision-maker (SDM) must receive rights advice. Rights advice is an important component in the system of checks and balances established under the *MHA* and its regulations for the protection of the rights of the individual.

The role of the rights adviser is specified in the *MHA* and its regulations. The rights adviser will explain to the individual the significance of the form which has been signed and their options if they disagree with the form. If instructed to do so, the rights adviser will assist the individual to apply for a hearing before the Consent and Capacity Board to review the legal finding, obtain a lawyer and apply for financial assistance from Legal Aid Ontario. Rights advice may only be provided by a person designated under the regulations as a rights adviser.[2]

The *MHA* was the first piece of health-related legislation to require that information be provided to a patient regarding their legal status. Rights advice was not always a part of the checks and balances contained in the *MHA*. Rights advice was embodied in the *MHA* as a result of the Canadian *Charter of Rights and Freedoms*,[3] most of the provisions coming into force on April 17, 1982. Among other things, it guaranteed every Canadian the right, on being detained, to be told the reason for the detention, and to be told of his or her right to retain and instruct legal counsel without delay. Section 15 of the *Charter*, the equality rights section, was delayed three years to give the federal and provincial governments time to review all legislation and amend it to comply with the *Charter*. The review of Ontario's legislation resulted in a number of changes being made to the *MHA* to ensure adequate due process protections to inpatients of psychiatric facilities whose rights were in some way suspended.

In 1986, rights advice became mandatory for individuals who were detained as involuntary patients. Since 1986, the number of mandatory rights advice situations has changed due to legislative changes. When the *Consent to Treatment Act* (*CTA*),[4] the *Substitute Decisions Act* (*SDA*),[5] and the *Advocacy Act*[6] were proclaimed on April 3, 1995, the number of rights advice situations increased from 8 to 29. The situations were a combination of mandatory rights advice (i.e., involuntary patients) and rights advice at the request of the person impacted by the loss of decision-making authority (i.e., incapacity to make decisions about medical treatment). Rights advice was provided in psychiatric facilities and in the community in a variety of situations specified in the *MHA*, *CTA*, and *SDA*. On March 29, 1996, the *Advocacy, Consent and Substitute Decisions Statute Law Amendment Act, 1996*[7] came into force and rights advice was limited to eight mandatory situations under the *MHA* and its regulations.

Although the situations have changed since 1996, there are still eight mandatory rights advice situations under the *MHA* and its regulations. They are:

- a physician's decision to admit an individual as an involuntary patient, or to change the patient's status to involuntary (Form 3);
- a physician's decision to continue the patient's involuntary status (Form 4);
- a physician's decision that the patient is incapable to manage his/her property (Form 21);
- a physician's decision that the patient's incapacity to manage his/her property must continue (Form 24);
- a physician's decision that the patient is incapable to consent to treatment of a mental disorder in circumstances set out in the regulations to the *MHA* (Form 33);
- a decision that the patient is incapable to consent to the collection, use or disclosure of his/her personal health information in circumstances set out in the regulations to the *MHA* (Form 33);
- when a 12-15 year old is admitted to a psychiatric facility as an informal patient (Form 27); and
- before issuing or renewing a CTO, a physician must be satisfied that the individual subject to the CTO and his/her SDM, if any, have consulted with a rights adviser and have been advised of their legal rights (Form 49).

Rights advice is a formal process provided by designated persons and is only provided in the eight mandatory situations listed above. Other individuals who have their decision-making authority abridged do not have access to a rights adviser. They may, however, be entitled to "rights information." The *Health Care Consent Act, 1996* (*HCCA*),[8] requires a health practitioner to provide rights information to an individual who has been found incapable to consent to treatment. The health practitioner provides the individual with information regarding the consequences of the finding as specified by the guidelines established by the health practitioner's professional college. Thus, for example, a physician who finds a resident of a long-term care home incapable regarding a treatment must provide the individual with the requisite information. This rights information includes the decision which has been made, the consequences of the decision, the right to challenge the decision, and assistance if the individual wishes to challenge the decision. There is recognition that individuals have the right to be informed of decisions which impact on the delivery of their health care and the right to challenge decisions with which they disagree.

There are several court cases which discuss the right of an individual, whose decision-making authority is being limited, to receive information regarding their rights and options. The individual who is making the decision to limit the individual's decision-making authority must be aware of their responsibilities and be diligent about providing the individual with the required information. In the case of *Re Koch*,[9] the court held that the individual must be informed of the right to refuse to speak to an evaluator under the *HCCA* and must be informed of the significance of a finding of incapacity to consent to admission to a care facility.

The case of *M.(A) v. Benes*[10] firmly established the obligation placed upon the health practitioner seeking a substitute consent for treatment to inform SDMs of the principles which must be followed when making a decision on the incapable individual's behalf. The SDM must follow the principles of decision-making as outlined in section 21 of the *HCCA*.

The *Long-Term Care Homes Act, 2007*[11] received royal assent on June 4, 2007, but only two sections are in force. The balance of the *Act*, including two new rights advice situations, will come into force on proclamation. Before a resident of a long-term care home can be transferred to a secure unit on the consent of a SDM, a rights adviser shall meet with the resident to discuss the right to apply for a hearing before the CCB. The rights adviser shall also meet with an individual who is being admitted directly to a secure unit with the consent of their substitute decision-maker. Upon the individual's request, the rights adviser shall assist the individual to apply to the Consent and Capacity Board for a determination whether the SDM has complied with the principles of decision making as set out in the *HCCA*. The Ministry of Health and Long-Term Care has not announced who will provide the rights advice in these two situations.

There is a growing recognition of the right of the individual to be informed of the consequences of decisions made by health practitioners and others involved in their care when the result is a limitation of their decision-making authority. This recognition is particularly important where the individual is vulnerable or is in a situation where they will require assistance to exercise their rights. To what other areas might the concept of rights advice be expanded for the protection of the individual? Rights advice might be expanded when an individual is found incapable to consent to a treatment where the individual is in one of the following circumstances:

- children in the care of Children's Aid Societies or living in group homes;
- residents of long-term care homes; and
- inmates of provincial and federal custodial facilities.

Rights advice is essential to the preservation of due process for individuals whose rights are suspended under the *MHA* and other legislation. We must be diligent in observing the rights of others and providing opportunities for the vulnerable and those in difficult circumstances to exercise those rights. Perhaps it is time to consider an expansion of the obligation to provide rights advice or "rights information" to other segments of our vulnerable population.

[*] Linda Carey is the Manager of Community-based Rights Advice Services at the Psychiatric Patient Advocate Office.

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1 R.S.O. 1990, c. M.7.
2 Sections 14 through 16 pertain to rights advice and rights advisers, *Mental Health Act Regulation*, R.R.O. 1990, Reg. 741.
3 Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), c. 11 *(Charter)*.
4 S.O. 1992, c. 31 (CTA), repealed by S.O. 1996, c. 2, s. 2.
5 *Substitute Decisions Act, 1992*, S.O. 1992, c. 30 (SDA).
6 *Advocacy Act, 1992*, S.). 1992, c. 26.
7 S.O. 1996, c. 2.
8 *Health Care Consent Act, 1996*, S.O. 1996, c. 2.
9 *Re Koch* (1997), 33 O. R. (3d) 485 (Gen. Div.).
10 *M.(A) v Benes* (1999), 46 O. R. (2d) 271 (C.A.).
11 *Long-Term Care Homes Act, 2007*, S. O. 2007, C. 8.

STRUGGLES, CHALLENGES AND ACCOMPLISHMENTS OF DEAF, DEAFENED AND HARD OF HEARING PEOPLE

Gary Malkowski[*]

The Canadian Hearing Society (CHS) is an agency which has worked with and for people who are culturally Deaf, oral deaf, deafened and hard of hearing for 68 years. We operate in 27 offices across Ontario. CHS strives to develop high quality and cost-effective services in consultation with national, provincial, regional and local consumer groups and individuals. A complete range of our services, including CONNECT Mental Health Services, can be found on our website (www.chs.ca).

CHS is the leading provider of services, products and information that remove barriers to communication, advance hearing health, and promote equity for people who are culturally Deaf, oral deaf, deafened and hard of hearing. CHS has sent many submissions to assist all levels of government in addressing barriers, gaps, needs and recommendations in support of Deaf, deafened and hard of hearing individuals with mental health issues and challenges and persons with disabilities. We continue to educate the public, including all level of government, through public consultations, and the policy decisions that will eventually result from them. Our education efforts should serve to help Canadians with disabilities, including Deaf, deafened and hard of hearing Canadians with mental health issues, while also increasing public awareness about the stereotypes and negative attitudes associated with mental health issues.

All CHS offices see consumers who:

- have no income, no home, no food, minimal literacy and are living on the street;
- are currently experiencing or have experienced physical and sexual abuse during childhood and adolescence;
- arrive at our offices in emergency situations, sometimes depressed and suicidal, needing an immediate response to protect their safety;
- have mental health and addiction issues;
- are experiencing or have experienced discrimination in workplace and other public services;
- lack education resulting in a poor understanding of the legal process;

- have a great deal of frustration with the scarcity of qualified sign language interpreters or qualified real time captioners resulting in delays of Children's Aid Societies meetings, investigations by police and court hearings; and
- have minimal understanding of the Ministry of Children and Youth Services' Provincial Advocate for Children and Youth, Ontario Ombudsman, Ontario Human Rights Commission and Human Rights Tribunal's complaint and investigation procedures and request assistance in navigating the entire process, from intake to prosecution.

Recent studies report the incidence of sexual abuse in various samples of the deaf population to be between 11% and 54%, certainly higher than the published data for the population in general. LaBarre suggested that the incidence of sexual abuse for children who are deaf or hard of hearing could reach as high as 92%.[1]

These research studies report that deaf children are more vulnerable to abuse than the general population. Factors involved in their vulnerability or susceptibility centre around communication ability and communication access, especially if the deaf children have hearing parents or are enrolled in school programs where communication access is limited.[2]

The Well-Being of Deaf and Hard of Hearing Children and Youth and Preventative Mental Health Strategies Coalition was formed last year. The members of the coalition are very concerned that deaf and hard of hearing children are falling between the cracks in health, social service and educational systems that seem ill-designed for them.

The result is that Deaf and hard of hearing children are falling behind educationally, socially and psychologically. As adults, they often do not live up to their employment potential and become unnecessary burdens on the health and social welfare systems.

Unfortunately, language deficiencies lead to being labelled with learning difficulties. In some cases there is no cognitive disability; in others, learning disabilities are compounded by language deficiencies. In both cases, it is too late for the language deficit to be repaired which results in enormous costs. Furthermore, it has been documented that deaf children with cochlear implants who receive sign language instruction become proficient at both the spoken language and the sign language that they are exposed to.

There is ample evidence that Deaf adults are over-represented amongst the unemployed and under-employed. All of this is so unnecessary and a waste of human potential, never mind an unnecessary tax burden on Ontarians.

Some of the solutions to these problems are neither complicated nor expensive. The solutions represent best practices and have demonstrated and positive outcomes. The solutions also represent the enactment of the Canadian *Charter of Rights and Freedoms*[3] (i.e., the Supreme Court of Canada's decision in *Eldridge v. British Columbia*[4] and the Saskatchewan Provincial Court's decision in *Farnham v. Saskatchewan*[5]) in relation to Deaf and hard of hearing children.

CHS has been actively involved for many years in advocating for effective legal protection for the rights of persons who are culturally Deaf, deaf oral, deafened or hard of hearing. From 1980-82, CHS was an active member of the Coalition on Human Rights for the Handicapped. That Coalition successfully fought to get the rights of persons with disabilities added to the Ontario *Human Rights Code*.[6]

From 1995 to 2005, CHS was an active member of the Ontarians with Disabilities Act Committee. That coalition successfully advocated for the enactment of the *Ontarians with Disabilities Act, 2001*[7] and the *Accessibility for Ontarians with Disabilities Act, 2005*.[8] We are now similarly involved with the ODA Committee's successor, the Accessibility for Ontarians with Disabilities Act Alliance 2005.

In 1997, CHS along with the Council of Canadians with Disabilities and Canadian Association of the Deaf was an intervenor in *Eldridge v. British Columbia*, a landmark case in which the Supreme Court of Canada ruled unanimously that Deaf Canadians are entitled to equal access and equal benefit under the *Human Rights Code*. *All services, funded directly or indirectly by government must be equally accessible and of equal benefit to deaf, deafened and hard of hearing Canadians, as they are to hearing Canadians*. As result of the Supreme Court of Canada's *Eldridge* decision, the Ministry of Health and Long-Term Care established Mental Health Services and Ontario Interpreting Services After-Hours Emergency Interpreting Services. CHS created 26 new Mental Health Counsellor positions

The principle that discrimination can accrue from a failure to take positive steps to ensure that disadvantaged groups benefit equally from services offered to the general public is accepted in the human rights field.

CHS has submitted several briefs on substantial federal and provincial pieces of legislation and regulations that assure people with disabilities the right to access and equitable treatment. The newest addition to these requirements is the August 11, 2006 Federal Court decision in *Canadian Association of the Deaf v. Canada*.[9] In his ruling the Honourable Mr. Justice Mosley wrote:

> As Canadians, deaf persons are entitled to be full participants in the democratic process and functioning of government. It is fundamental to an inclusive society

> that those with disabilities be accommodated when interacting with the institutions of government. The nature of the interests affected is central to the dignity of deaf persons. If they cannot participate in government surveys or interact with government officials they are not able to fully participate in Canadian life.

Although technically the Federal Court decision only applies to the Government of Canada, on a substantive and ethical level, the decision applies to municipal and provincial governments. Should the municipal and provincial governments ever be challenged in court on a similar basis, there is little to differentiate their provision of services, as well as involvement in the democratic process and functioning of government with respect to deaf and hard of hearing persons as required under the *Charter of Rights and Freedoms*.

Without the knowledge and understanding of how to use effective political, legal and lobbying strategies to influence government policy makers, the policies and practices set by all levels of the public and private sectors will continue to discriminate against persons with disabilities, including Deaf, deafened and hard of hearing individuals at tremendous human costs.

As baby boomers age, the number of seniors in Canada will increase dramatically, which could cause an unprecedented strain on the system, including community social services, health, and mental health services. It is critical that Canada plans for this demographic shift, and discrimination prevention should form part of that planning process in all levels of government actions. In particular, investments in tools and approaches used to implement successful political, legal, lobbying and media strategies to preserve distinct services and accommodations required by persons with hearing loss could considerably reduce the cost of leaving conditions unaddressed and contribute markedly to the majority of our seniors with disabilities aging well and in place.

Working together we can continue to provide public education at all levels of government on: the needs of persons with disabilities, including Deaf, Deafened and Hard of Hearing people for key successful lobbying; political, legal, media strategies include documenting barriers and discrimination; using effective individual and systemic advocacy approaches, follow-up actions, using effective lobbying, political, legal and media strategies and providing public education. Struggles and challenges will continue to lead to many achievements and many opportunities.

*Gary Malkowski is Special Advisor to President, Public Affairs, The Canadian Hearing Society.

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1 LaBarre, A (1998). Treatment of Sexually Abused Children Who are Deaf. *Sexuality and Disability*, 13(2), 97-106.

2 Sullivan,P., Vernon, M., and Scanlan, J. (1987). Sexual Abuse of Deaf Youth. *American Annuals of the Deaf*, 132, 256-262.

3 Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.) 1982, c. 11.

4 [1997] 2 S.C.R. 624.

5 *Provincial Court of Saskatchewan, The Child and Family Services Act of Saskatchewan and Ryley Allen Farnham*, the Honourable Justice Orr, P.C. J., August 19, 2005.

6 R.S.O. 1990, c. H.19.

7 S.O. 2001, c. 32.

8 S.O. 2005, c. 11.

9 2006 FC 971 (F.C.T.D.).

TELEPSYCHIATRY: IMPROVING ACCESS TO CARE

Robbie Campbell*

Introduction

Introducing telepsychiatry was a rather lonely and isolated task. It was not until 1992, working with Nortel and their "visit" program, that we were able to use a video and audio screen to enable a physician to "hook up" with their patients at a distance. By 1994, we had connected an Oakville and London office and began seeing patients for follow-up visits. This computer-based system did not have the resolution of today's monitors, but gave us a unique opportunity to begin to evaluate its effectiveness and, most importantly, how patients "viewed" the service. Needless to say, it was well received. With a grant from Eli Lily and Glaxo, we were able to set up a new delivery service from the then London Psychiatric Hospital to its Simcoe clinic and from a London office clinic to the Homewood in-patient Eating Disorder Unit in Guelph. The "Duke of Edinburgh Commonwealth Study Conference" requested that we demonstrate our new mental health delivery system utilizing cutting edge technology to future commonwealth leaders. This innovative Canadian developed state of the art technology and its medical applications were then taken back to the participating commonwealth countries so they could address best practices with regard to using telepsychiatry to service rural communities. By 1999, we were able to secure a Telecommunications Access Partnership (TAP) grant of $500,000 from the Ontario government that allowed us to expand the London Psychiatric Hospital outreach program to eleven Southwestern Ontario communities on a trial basis.

CHIPP Grants

In 2000, Regional Mental Health Care - London (RMHC-London) was successful in securing a $2.5 million Canada Health Infrastructure Partnership Program (CHIPP) grant to pilot "Project Outreach", an Ontario wide telepsychiatry system that had the capacity to include hospital, clinic, university and First Nation sites.

Project Outreach partners included the Departments of Psychiatry at Western, Toronto, Ottawa and McMaster universities, as well as the Ontario Psychiatric Outreach Program that traditionally provides fly-in service to remote communities. The research and evaluation component of the project was headed by the Lawson Health Research Institute in London, along with Telesat and the Canadian Research Centre in Ottawa. The Chippewa of the Thames took a lead role in addressing the use of satellite technology and its feasibility in delivering mental health services to First Nation communities. Project Outreach successfully completed its pilot project on December 31, 2003.

The North Network, the Eastern Ontario Telehealth Network and the South Western Ontario Telehealth Network (later called Videocare) were also awarded "regional" CHIPP grants for their catchment areas. The Project Outreach grant was dedicated for telepsychiatry only, but included a province wide delivery system. At the conclusion of these four CHIPP grants, the government undertook to establish one province wide network called the Ontario Telemedicine Network (OTN) that included all medical specialties, including psychiatry. OTN was officially launched on April 1, 2006.

Benefits of Telepsychiatry as an Adjunct to Current Clinical Care

Project Outreach was clinically driven and logged some 3,920 patient interventions. Random patient satisfaction forms indicated a high level of satisfaction and that telepsychiatry was as effective as face-to-face psychiatry. Of note is the fact that the project utilized telepsychiatry to compliment, rather than compete, with conventional psychiatry.

By reducing the need to travel, Project Outreach found that telepsychiatry increased the hours of treatment available and increased the speed with which the services could be delivered thus reducing wait times. In addition, with earlier interventions, symptoms could be more easily managed in the community without the need for hospitalization.

Project Outreach also provided funding for the telepsychiatry network that sponsored the research of Dr. Richard O'Reilly and his associates that gave further evidence of the value of telepsychiatry when compared to face-to-face visits. His initial project between London and Thunder Bay now continues as an ongoing adjunct telepsychiatry outreach service to this Northern community. Dr. Ladi Malhotra, a lead psychiatrist with Project Outreach, continues to provide a valued clinical service to Simcoe, Owen Sound and Thunder Bay. Dr. Margaret Steele was able to utilize Project Outreach technology to compare live versus televideo continuing medical education programs and the Department of Psychiatry has since greatly expanded the number of communities that are included in its delivery of education to Southwestern Ontario through the OTN.

Home Care Monitoring - Interest from the European Space Agency

With lessons learned from Project Outreach, the European Space Agency (ESA) and its partners provided a $750,000 grant for Remote Assertive Community Homecare (REACH) to study a hybrid satellite, land-line system for home care monitoring. The partners include Lawson Health Research Institute, Telesat, Canadian Space Agency, VaaSah, Community Research Center and RMHC-London with the Schulich School of Medicine and Dentistry at the University of Western Ontario. Project Outreach studied twenty patients who were followed at home by the Oxford Assertive Community Treatment Team (located in Woodstock) with the team psychiatrist centered at RMHC-London. Both the team and the psychiatrist could be connected to the home site. Privacy, confidentiality and security were assured and there was a high level of patient satisfaction. The travel time reduction and early intervention strategies were shown to have a 20% cost saving benefit that indirectly allowed the delivery system to address wait times more effectively. The REACH-ESA project was completed on December 31, 2007 with the recommendation that home care should become part of our mental health delivery system and help us with monitoring those patients who need more frequent "visits" to remain living in the community as opposed to an institution and for those patients who are deemed Alternate Level of Care (ALC) and occupying a hospital bed only because there is no "appropriate" housing.

A City-Wide Telemedicine Steering Committee has been established with city and regional stakeholders, including the hospitals and the Schulich School of Medicine and Dentistry, to ensure that home care, other ongoing local needs and future requirements for telehealth are being addressed.

Current OTN Network

The OTN now provides an Ontario wide hospital-to-hospital connection and is available for education, administration, teaching and clinical purposes for some 440 sites across the province. In 2007, OTN conducted over 32,000 clinical consultations. We applaud their continued interest in expanding telepsychiatry and hope they will incorporate some of the lessons we have learned at RMHC-London.

Conclusion

Our telepsychiatry initiatives are on the leading edge of utilizing newer technologies to provide an improved quality of care for our patients. With current land-line and satellite hybrid systems, we are able to service rural and remote communities that traditionally have not had the same access to care. We are now able to bring a host of clinicians right to the comfort of a patient's home and have customized monitoring for personal needs. In this way, telepsychiatry will compliment a person's current support systems and help patients with day-to-day adjustments which, in turn, will help you to maintain and even improve a person's quality of life.

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[*] Dr. Campbell was a former professor of psychiatry at the University of Alberta and former chief of psychiatry at Oakville Trafalgar Memorial Hospital prior to coming to London, Ontario in 1994. He is currently the physician lead for the Assessment Program and the Coordinated Access Team at Regional Mental Health Care London and St. Thomas. In addition, he is an assistant professor of psychiatry, the Schulich School of Medicine and Dentistry, University of Western Ontario and has conducted his telemedicine research as a research scientist with the Lawson Health Research Institute.

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MORE WAYS TO HEAL: USING COMPLEMENTARY AND ALTERNATIVE APPROACHES IN MENTAL HEALTH

Ted Lo[*] and Arlene Moscovitch [**]

Extreme emotional distress, tentatively diagnosed as a first psychotic break, had forced Larissa to drop out of her university drama program in her second year. The medication she was taking left her feeling disoriented, emotionally numb and "unable to recognize myself." Though she was eager to return to school, her psychiatrist advised her to attend a day program instead, as well as having individual counseling and therapy sessions. Larissa complied but felt frightened by the tentative diagnosis offered, de-spirited by her medication's side effects and completely lacking in self-confidence. A mentor introduced her to Laughercize, a loose combination of laughter yoga, improv and tai chi. After a bout of initial panic, Larissa's Laughercize class became the highlight of her week. She could bond with the other people in her group without having to talk – a welcome change from her daily "groups." With more oxygen and endorphins coursing through her system, she felt energized and "lighter" after each class and able to rest without resorting to sleeping pills. Not only did she slowly regain her self-confidence, she began sharing some of the exercises with other people in the day program and eventually trained as a Laughercize instructor. Now, 18 months later, she is off her medication, back at school full-time, taking a course in Mindfulness meditation and working part-time at her long-time restaurant job. Her psychiatrist was so impressed by Larissa's positive response to Laughercize that she has asked Larissa to lead some sessions with the day program's staff for their own self-care.

Larissa is far from the only person facing a mental health challenge to explore possible forms of relief offered by complementary and alternative health care. This trend is a reflection of the growing use of alternative forms of treatment and products among the general population. A 2005 Health Canada study of consumers' use of natural health products found that 71% of the population surveyed used these products.[1] Almost half of the people suffering from anxiety and severe depression have tried some kind of alternative or complementary modality. Indeed, these are among the top four conditions leading people to use complementary and alternative medicine (CAM).

Many consumers are dissatisfied with the limited efficacy of conventional treatment. As well, many people are concerned about the side effects of conventional treatment. For example, about 21% of consumers reported some side effects with natural health products, while 41% reported side effects with conventional medications.[2]

The Range of Complementary and Alternative Therapies

There is a wide range of CAM applicable to mental health issues, with uneven, but increasing research evidence supporting their efficacy. A partial list of useful modalities for various conditions includes:

- Anxiety – herbs (e.g., kava, valerian), aromatherapy (e.g., lavender);
- Stress – herbs (e.g., ginseng, ashwaganda);
- Depression – herbs (e.g., St. John's Wort), supplements (Omega 3 essential fatty acid), acupuncture, mindfulness meditation;
- Addiction – acupuncture, qigong;
- Attention deficit disorder – evening primrose, ginseng;
- Trauma – eye movement desensitization and reprocessing (EMDR); and
- Psychosis – rauwolfia, L-stepholidine.

Complementary and alternative medicines present more than just an additional armamentarium to fight illnesses. These approaches require that we engage nature's powers of healing in a way that differs greatly from the biomedical model. That distinction is particularly evident when one starts to appreciate the importance of lifestyle changes – including nutrition, exercise and meditation – for people facing mental health challenges.

Mental Health through the Lens of Traditional Cultures

Many of the CAM 'modalities' have their roots in traditional understandings of health and healing. In every culture, at every point in time, people have had to deal with emotional, mental and spiritual crises. The western model of psychiatry is a relatively recent phenomenon and the use of pharmaceutical drugs to manage what are sometimes seen as genetically-based, universal and incurable diseases is an even more recent development.

Most traditional cultures have their own explanations for the causes of mental illness, such as spirit possession or a psychic attack motivated by envy. They also have devised rituals and protocols to help people through these times of crisis or the aftereffects of trauma. The rituals may vary but certain common elements stand out. The use of highly rhythmic movement and chanting or drumming helps people enter a trance-like state. The rituals are almost always collective in nature and help reaffirm the afflicted person's position as a member of his or her society and the cohesion of the supporting culture. These cultures also often make use of healing herbs and techniques, such as massage to support a return to a state of harmony.

Ayurveda, the Indian "science of life," is the oldest medical known system, dating back more than 5000 years. Its focus is to restore mind-body-spirit balance by using a variety of stress management techniques, including yoga, massage, aromatherapy, meditation and a diet geared to an individual's particular bio-energetic "fingerprint."

Traditional Chinese medicine, also with a history of centuries of continuous use, aims at restoring the upset balance of yin and yang energies through dietary modifications, herbs, acupuncture, and exercises such as chi gong and tai chi.

Aboriginal healing has been around for millennia and treats emotional problems, including trauma and addictions, through herbal medicine and rituals that may include sweat lodges, purifying ceremonies, drumming and prayer.

Why Are These Approaches Important?

What we are currently witnessing is a cultural shift and the public is leading the way, with healthcare professionals following behind. Alternative and complementary approaches are hardly new – Hippocrates urged us to "honour the healing power of nature," his fellow-Greek Galen said "the physician is only nature's assistant" and Thomas Edison predicted "the doctor of the future will give no medicine, but will interest his patients in the care of the human frame, in diet, and in the cause and prevention of disease." The major advances in biomedicine in the past century have blinded us to medicine's own long history. As it is, over 80% of the world's population relies on herbs and traditional medicine.[3] Even in Europe (particularly Germany) and Asia (for example, China), these approaches are very much a part of mainstream medicine, and doctors are educated in such practices.

Although the range of alternative and complementary therapies is diverse, they do share some common characteristics:

- In contrast to the biomedical model which focuses on disease and external intervention, the complementary and alternative healing modalities work with the concept of "balance," a natural state of harmony, to which the body's own self-healing mechanisms are always striving to return. It is that inherent capacity for resilience/recovery/health that these approaches try to stimulate and strengthen;
- Their holistic orientation means that people are seen as a combination of physical, mental, emotional and spiritual energies, influenced by their social and ecological environments. Interventions are aimed at all those different levels;
- They involve patients as active participants in their own healing. Patients are empowered but also

expected to assume responsibility for their healing; and

- Beyond eradicating disease, they focus on recovery - each person's journey is unique and multi-faceted and the state of balance achieved, indeed the very definition of balance, may be different for everyone. As well, the goals of alternative and complementary therapies are prevention and well-being.

Issues

With this emerging cultural change, the healthcare 'market' has created a plethora of 'products' – not just herbs and supplements, but also therapeutic modalities ranging from Reiki to past life regression and beyond. How do consumers know which is the most appropriate therapy or product for them?

To address this issue, Health Canada has established the Natural Health Products Directorate, but the impact on consumers is still quite limited. Though consumers are encouraged to discuss complementary approaches and products with their physicians and other healthcare providers, most mainstream professionals have no education in this area and may have a negative view of such practices. It is no wonder that even though two-thirds of patients are using both prescribed medications and some other approach concurrently to treat their distress, only one-third have disclosed that use to their physicians. [4]

Change is happening as younger healthcare professionals, who have some awareness of this cultural and paradigm shift, are demanding more information in this area. Community groups such as FACT (Friends of Alternative and Complementary Therapies Society) are also advocating for greater integration so that the richness and diversity of CAM may eventually lead to a new medicine for the twenty-first century. Beyond the many technological advances, such an expanded vision would need to tap into the combined wisdom of our history and cultures, so as to truly improve the health and well-being of our people now and in the generations to come.

For more information, please go to:

FACT (Friends of Alternative & Complementary Therapies Society), www.thefact.org

Alternative Medicine Foundation, www.amfoundation.org

Alternative Health News Online, www.altmedicine.com

Center for Mental Health Services Knowledge Exchange Network, http://mentalhealth.samhsa.gov/publications/allpubs/ken98-0044/default.asp

Safe Harbor, www.alternativementalhealth.com

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1 Baseline Natural Health Products Survey Among Consumers (Health Canada, 2005)
2 Ibid.
3 WHO Traditional Medicine Strategy 2002-2005, p.1
4 Baseline Natural Health Products Survey Among Consumers (Health Canada, 2005)

ACT: SUPPORTING EMPOWERMENT AND RECOVERY

Patricia Cavanagh*

The 25th anniversary of the founding of Ontario's Psychiatric Patient Advocate Office (PPAO) is a fitting time to reflect on Assertive Community Treatment (ACT) and how this model has promoted their shared goals of individual empowerment and recovery. I am delighted to have been invited to comment on how ACT in Ontario has joined with the PPAO to promote, empower and support recovery in those with serious and persistent mental illness (SPMI). Reflecting on the contribution to ACT in Ontario by Dr. Hugh Lafave, one of its "founding fathers," provides a starting point.

The ACT model was developed during the 1970s in Wisconsin in response not simply to the forces of deinstitutionalization, but to the observed phenomenon of people with severe mental illness successfully working toward recovery with the many supports provided on an inpatient ward, and then repeatedly destabilizing after discharge. These so-called "revolving door patients" were not being served adequately by the existing complex of care in the community. The ACT model developed by Stein, Test and Marx[1] sought to become a "hospital without walls" that would allow people with SPMI to achieve an improved quality of life with less dependence on institutions. A multidisciplinary team of health care providers would work with people "in vivo" rather than in the artificial setting of the hospital to provide individualized and multidimensional support.

The PPAO commenced its work in 1983, seven years before Ontario's first ACT team was established in Brockville by Lafave and colleagues. In 1996, having completed a study of the Brockville ACT experience, which found improved quality of life and lengthened community tenure among ACT clients, he noted that, "despite the difficulties experienced in trying to extend the assertive community treatment model in Ontario, there is room for optimism... ."[2] This was a period of ambitious mental health reform and increasing recognition of the rights of those whose lives were affected by Ontario's mental health laws. In this spirit, the decision was made in the late 1990s by the Ministry of Health and Long-Term Care to adopt ACT as an evidence based "best practice" and to fund teams throughout the province, many of them facilitating discharge of clients (or, in fact, residents) of provincial psychiatric hospitals. This significant addition to community based mental health services for the most seriously mentally ill dovetailed with restructuring initiatives affecting provincial psychiatric hospitals, as well as the introduction of Bill 68, introducing mental health law amendments that included provision for community treatment orders (CTOs).

Dr. LaFave's optimism was rewarded. Since 2000, 79 teams have been funded in Ontario. Figures from 2007 show that ACT clients with SPMI had spent an average of 67 days in hospital in each of the previous two years, and after admission to ACT teams, their time spent in hospital was reduced by 64% after one year, gradually increasing to 82% after six years.[3] But these changes to the mental health service field have been controversial - even fraught at times. In the words of LaFave et al, "the right people with the right dedication can make the worst structure succeed…(but) if workers are not client centred or committed to the model of service delivery, they can make the best structure fail."[4] Certainly ACT teams present at least great *potential* to "promote self-advocacy and self-determination," consistent with the mission of the PPAO.[5]

The early studies that Lafave looked to, and the next generation of research as well, supported ACT as an effective means of decreasing hospital use and improving quality of life.[6] A landmark Canadian study indicated that for the model to be economic in delivering care, patients with more than 50 hospital days per year should be the recipients of care.[7] However, concerns about rights infringements and fears of the model's potential to encourage intrusive and paternalistic care led to considerable fears and public debate.

This debate, occurring amongst diverse groups generally committed to the same goals of empowerment and recovery for the seriously ill, has largely settled. The ACT model in Ontario has flourished. Networks among teams give support to newly funded programs, with longer established teams mentoring new ACT workers. In 1998, the first Ontario ACT conference was held by St. Michael's Hospital in Toronto, leading to biannual multidisciplinary conferences. The Ministry's establishment and management of the "Technical Advisory Panel" on ACT was followed by the development of a coalition born of the enthusiasm and commitment of ACT professionals. This Ontario ACT Association became a driving force in the promotion of standards and collegial activity among Ontario ACT teams.[8]

In less than a decade, ACT in Ontario has moved from the pioneering work of the early teams to a substantial network of care. It has become hard to argue effectively against these new manualized teams, which "made it imaginable, and then practicable, for staff to go outside their offices to see patients."[9]

Debated as it may be, the basic tenets of ACT are client centred, and designed to empower and enable patients to reach the highly individualized goals of what has come to be known as "recovery" (however much some may still want to call it "psychosocial rehabilitation"). Essential elements of the approach include individualized care by specialists, flexible and long-term commitment to clients, building on strengths, meeting people in their own home or community and adapting to the needs of clients.10 The work of academics and advocates in analyzing the model has extended through more than two generations of research now as "fidelity measures" were extracted11 and tested against patient outcomes, and the model applied to distinct groups within the SPMI population. ACT has been challenged to adapt and has been modified to address the needs of, for example, the homeless, older and younger populations, forensic programs and concurrent disorders. In Ontario, teams with forensic designation have been targeting Ontario Review Board clients with special training and collaboration with Law and Mental Health Programs.

A focal point for the PPAO in its 25 years has been the involvement of mental health care consumers in their care, from the systemic to the clinical level. This has become a key element in the Ontario ACT teams, where the role of the Peer Specialist has been enshrined in the revised ACT standards as "someone who is, or has been, a recipient of mental health services for serious mental illness... (and) provides expertise that professional training cannot replicate." It goes on to note that these positions must be "fully integrated."[12] The contribution of ACT teams' Peer Specialists has extended across the tables around which ACT clinicians meet and clients speak, to the academic literature, and to conference presentations. Surely this is the legacy of Dr. Lafave, who in the 2003 article for the PPAO's 20th anniversary, along with his coauthors, insisted that, "the inclusion of consumers as full members of the team helps ensure that consumers' voices are heard and their rights are respected."[13]

A robust model for delivering health care must address a population's changing needs and society's changing expectations while keeping its focus on consumers. Critical appraisal and bold challenges from within and without will mark the future of ACT in Ontario, as it has marked its history. The PPAO is critical to this discussion of mental health service delivery on Ontario. In 2002, the PPAO published a report on a pilot project completed in conjunction with a group of Ontario ACT teams, which included a provocative research project and advocacy service that spoke to the needs of both teams and their clients.[14] ACT consumers and clinicians will benefit alike if further such collaborations are noted at the next celebration of the PPAO.

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COMMUNITY TREATMENT ORDER COORDINATORS – SMOOTHING THE PROCESS

Cathy Plyley*

With all change comes a time of development and learning. It has been approximately seven years since the changes to the *Mental Health Act* were proclaimed in December of 2000.[1] Within the amendments was the option of a community treatment order (CTO). The rationale of the CTO was to provide a mechanism to support adherence to treatment in the community by individuals with a mental illness by providing "a person who suffers from a serious mental disorder with a comprehensive plan of community based treatment or care and supervision that is less restrictive than being detained in a psychiatric facility."[2]

Aside from the political and ethical issues related to CTOs, the very practical aspects of education, facilitation and administration loomed as an obstacle for attempting to use this tool. Procedurally, the development of a CTO is a process with many forms, timelines and processes. An extensive program to educate all stakeholders about the changes to the *Mental Health Act* would, in itself, be an onerous task requiring consistent and persistent education. Clearly, much information regarding the process and, more importantly the benefits and limitations of CTOs, would be required to allow for acceptance of this tool in the mental health community.

Two of the criteria for implementing a CTO – that the person is able to comply with the community treatment plan and that the treatment care and supervision required under the CTO are available in the community – necessitated a response prior to the use of CTOs.[3]

The availability of a community case manager was deemed critical to the success of discharge. Community case management and other community based services are an essential component of integration in to the community for individuals suffering from a mental illness. A concern was voiced that clients who were not on CTOs would lose or receive less services than those on them if existing services were required to provide an intensive level of service for those on CTOs. To address these concerns regarding the implementation of the orders, the Ministry of Health and Long-Term Care funded positions for CTO Coordinators and CTO Case Managers.

Each region under the Ministry's boundaries received funding for a CTO Coordinator. Each region also received funding for a CTO Case Manager. At first glance, this seemed to be an appropriate distribution. Some areas found this unmanageable due to geographical distance and as a result, some hybrid positions exist with Coordinators and Case Managers splitting the positions which allows for a dual role with more realistic area boundaries. Toronto's funding was unique in that the funding was for a CTO Coordinator Manager, eight Coordinators and a team of Case Managers which is reflective of the number of hospitals.

The hiring of each Coordinator was done by individual hospitals with little input from the Ministry. The spectrum of qualifications and experience for the role is broad and has been an asset as the program has developed.

In November of 2001, a session was held in Toronto to provide a basic training session for the Coordinators and Case Managers. A job description was developed which set out the broad tasks for the Coordinators, consisting largely of education and the coordination of services within the hospital settings and community agencies.

Early challenges in developing these roles related to the philosophical dissidence of utilizing a CTO in agencies where the mandate and philosophy were based upon a voluntary relationship between the service provider and the client. Some case management services were also unprepared to work with a client who was considered incapable to consent to treatment. To be dealing with substitute decision makers for the first time was, for some, a complete change of responsibility.

In some agencies, the client on the CTO was the same client that the agency had worked with for many years. A CTO for the client created a more hopeful outlook, as the agencies no longer had to deal with the issue of maintaining hospital-based linkages as this was now available in a more formalized and collaborative fashion.

The Coordinators and Case Managers are not linked positions and, with few exceptions, those two positions are in facilities with divergent approaches. Relationships between the hospitals where the Coordinators are placed and the agencies are holding the case management positions are unique. In the situations where the positions had been split due to geographic size, the two positions might be placed together, or actually be one individual providing a dual role.

There were no individuals in the Ministry with the role of providing interpretation or guidance so the Coordinators are left to create the role to fit their regions. Each region's mental health system has a distinct and unique culture in terms of delivery of service and interactions between agencies.

Education about CTOs is the Coordinator's role. The task of providing enough information to garner support to at least try this new tool was onerous at times. Prior to the development of the Coordinator role, the early experiences of clinical teams as they issued the first CTOs were fraught with difficulties, including extensive, complicated and lengthy Consent and Capacity Board hearings. As these experiences were relayed to stakeholders around the province, CTOs became a feared option for most physicians who anticipated a legal nightmare. The task for Coordinators was to provide practical support by way of assisting with all aspects of the CTO, including coordinating all stakeholders in developing the plan and ensuring that paperwork met the standards required for scrutiny by the Consent and Capacity Board.

Education for clients and substitute decision makers was critical. The fear and misconceptions surrounding CTOs were tremendous. In my first education session for clients, one individual would not give their name as they believed I was recording names to make a list of those with psychiatric illnesses who were not in hospital. This individual believed that anyone could be targeted and pulled off the streets and placed on a CTO. The original concept was that the plans would be so restrictive that the movements and day-to-day activities of people with psychiatric illnesses would be severely limited. Within the first year, over 100 education sessions were completed in London alone. Educating all stakeholders at the same time was important to help break down the stigma and sense of "doing it to" the clients.

In the *Report on the Legislated Review of Community Treatment Orders, required Under Section 33.9 of the Mental Health Act* completed by Dreezer and Dreezer Inc., Michael Bay, one of the primary consultants for the review noted: "The CTO Coordinators across the province have proven themselves to be an indispensable resource at all stages of the CTO process. They educate, coordinate, and facilitate the process. They provide essential assistance to physicians and are a key link between clients, families, hospitals and community agencies."[4]

Through informal networking, Coordinators have developed a role which involves supporting the treatment teams and clients on CTOs, as well as providing much needed information to substitute decision makers.

The role of CTO Coordinators across the province continues to evolve as we assist in developing the establishment of working partnerships to support the clients and teams who are utilizing the organized plans of a community treatment order. Coordinators and administrators have identified a need for research and consistent data collection.

With the exception of a few areas in the province, community treatment orders have become an accepted option in discharge planning as there is a general acceptance of them as a useful tool. Repeatedly, the issue of availability of community resources is raised in relationship to discharge from hospital or establishing an environment which will support those individuals in the community with a mental illness.

Two reviews of CTOs have now been completed. The first review, as noted above, was completed by Dreezer and Dreezer and it covered a broad spectrum of issues related to CTOs. In total, 45 recommendations came from that review. Many of the recommendations refer to the role of a CTO Coordinator. To follow up, the Ministry responded and contracted Power Analysis Inc. to specifically address specifically the CTO Coordinator's role and function. This study explored five recommendations in the Dreezer and Dreezer report concerning the roles and responsibilities of CTO Coordinators to help the Ministry determine appropriate responses. This has now been completed and we are anticipating the release of this report from the Ministry as the recommendations will assist in moving forward in assisting vulnerable individuals and their support networks to establish realistic plans for community support as they return to, or, establish lives in the community.

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1 R.S.O. 1990, c. M.7.

2 *Ibid.*, s.33.1(3).

3 *Ibid.*, ss.33.1(4)(c)(iv) and (v).

4 Dreezer and Dreezer Inc. for the Ontario Ministry of Health and Long-Term Care, (December 2005), p.18. http://www.health.gov.on.ca/english/public/pub/ministry_reports/dreezer/dreezer.html.

A SEVEN YEAR ITCH: CTOS, COMMITMENTS AND ME

Lucy Costa [*]

This piece is dedicated to the next flourishing generation of Mad folk[1] who will refuse, resist and rebel.

Community treatment orders (CTOs) have been in full force in Ontario for over seven years. During those seven years I've been on the sidelines, involved and watching how the rise of psychiatric rights and recovery discourse has been coupled with a rise in mandated drug treatment. Early on in the Ministry of Health and Long-Term Care's (MOHLTC or Ministry) legislated review of CTOs, it states: "*Our findings and recommendations will almost certainly find both supporters and detractors because that is the nature of the debate about CTOs. For example, those who would like to see CTOs abolished completely because they see CTOs as violating an individual's rights would probably still want to see them abolished.*"[1]

Ironically, these two sentences appear on the same page as an admission that the review does not take the place of properly structured research. It also says that more CTO co-ordination is needed with less enforcement obstacles for psychiatrists. This begs the question: why wouldn't there be a strong, ongoing critique of CTOs? The debate on CTOs, and psychiatric practices in general, remains contentious because coercion is troubling both in CTOs and in the day-to-day automation of institutional life. As an outreach worker, I often hear patients' fears and complaints regarding how staff use security guards as a means of enforcing compliance with medication and how drugs are the first remedy offered for distress above all other options.

The values of the *Charter of Rights and Freedoms*[2] are rendered meaningless when there is no real discussion about how legislation plays out on the ground for individuals it is meant to support. Under section 15 of the *Charter*, persons with a "psychiatric disability" are entitled to equal treatment and hopefully an analysis of historical disadvantage yet even when legal cases such as *Winko v. British Columbia*[3] or *Starson v. Swayze*[4] favour client rights, the conditions of their lives are seldom improved. Decisions and understandings on equality for person with a "psychiatric disability" varies drastically particularly if we do not have access to lawyers who understand madness, or mental health law.[5] I have attended hearings where counsel on behalf of the psychiatric patient brought no report, no questions and offered no defence to the incriminating questions posed of their client. Rights exist on paper but in practice are violated. When patients are courageous enough to come forward and complain, the grievance disintegrates into an account of "he said-she said" with the client usually feeling worse for having complained in the first place.

There are still not enough avenues for debate on the reasons people choose to refuse treatment and why people are turned off by some services. Mad people still don't have enough accessible representation in law or on committees, boards and commissions to ensure a balanced discussion of the issues. Even when we do participate we are expected to adopt and configure feedback so it suits the language and structure of the meetings which are run by people who have had years of academic or professional grooming on appropriate meeting conduct.

Commitment and Dissent

In 1997, I called up the former Queen Street Patient's Council to ask about the latest and most pertinent issues in mental health. I was a student then and not yet "out" as a crazy person. The staff spoke to me about a number of topics including the then very piquant issue of Bill 111, a private members bill, expected to amend the *Mental Health Act* in ways similar to Bill 68.[6] I was impressed with the Patients Council's expertise on such political matters, especially since I had never been offered any body politic during my own jaunts in the therapeutic state.

Prior to Bill 68 rearing its head in 2000, protests, press conferences, radio shows and other meetings by psychiatric survivors and other detractors had occurred from 1998 and well into 2001. The No Force Coalition (without a million dollar budget) was born in January of 1999 to address "stigma" type problems such as the commonly held stereotype that madness equals violence. In April 2000, the No Force Coalition wrote an open letter to members of Ontario's provincial parliament critiquing the current system, stating that: "*This exhaustive reliance on coercion in the guise of preventative care will fail people in crisis and drive them underground.*"[7]

In December of 2000, an advisory committee was created between the Centre for Addiction and Mental Health (CAMH) and the Canadian Mental Health Association (CMHA) to facilitate discussion on preventative treatment and debate on how to steer CTOs. Those early days of sceptical debate had the room filled with agencies such as the Psychiatric Patient Advocate Office, Community Resource Consultants of Toronto, Toronto Police Services Board, Street Health, Schizophrenia Society and COTA, just to name a few. The lunatic contingent was present via representatives from Patient Councils, such as the Ontario Association of Patient Councils and myself, a then employee representing the Queen Street Patient's Council and later the Empowerment Council.[8] The agenda, as set by CAMH or CMHA, centered on CTO coordination, case management, evaluation mechanisms and education-promotion opportunities. The advisory committee still discusses these general themes today. The room, once filled with active participants and critics, has now dwindled down to a group of five or less, operating more as a reporting vehicle than an advisory group.

The Long Anticipated Ministry of Health CTO Review

One of the positive features of sitting in on meetings during the first three years of CTO implementation was the anticipation and hope of exerting some meaningful influence over the mandated review of CTOs. The review, due three years into implementation, didn't actually get rolling until after four years, leaving a bad taste in our mouths about how seriously the government would take this review, particularly since the Ministry had conducted consultations about mental health reform with the *Making It Happen* report.[9] When the request for proposals was finally awarded to Dreezer and Dreezer, a number of psychiatric survivors and consumers were surprised that consultants working on behalf of CAMH and CMHA[10] were going to be involved in the evaluation process.[11] I flagged the issue at a meeting and was told that there was, in fact, no conflict per se but only a "perceived conflict of interest." I was told conflicts had been declared, the Ministry knew, and had approved. When I questioned the inclusion of a CAMH staff member, the team lead noted that this person was involved because he had a filing cabinet full of journal articles on CTOs. Perhaps it never occurred to the team that psychiatric survivors might also have a cabinet full of relevant literature – certainly the MOHLTC interview questions included an inquiry as to how consumers could be involved.[12] Several organizations, such as the Ontario Federation of Community Mental Health and Addiction Programs, had recommended that the successful bidder have an arm's length relationship from the Ministry or any CTO service provider.[13] Yet the contract was awarded to consultants affiliated with CTO service provision.

Even more interesting than the issue of conflict of interest itself was the response to simply raising questions about conflict of interest. Historically, for those wanting to do real advocacy and not just ghettoized peer work, challenging the purse strings has left us vulnerable to the potential threat of losing funding and power. I recall my co-worker sharing a story about a senior staff person at CAMH, who had approached her to inquire about whether she knew that I was raising the spectre of bias.[14]

Fortunately, other psychiatric survivors and consumer agencies also began to ask questions about bias. Dreezer and Dreezer later updated its website, but failed to acknowledge any real bias, when it announced: "*Perception of conflict of interest does exist in the minds of some* *individuals because CAMH/CMHA are recipients of government funding related to CTOs.*" Call us crazy, I guess.

The Need for Ongoing Dialogue about Patient Rights

CTOs have become the runaway train that keeps on going, but now with fewer pit stops. The MOHLTC review indicated that physicians were unhappy with the "lack of teeth" in CTOs, including for example, that the Form 47 (Order for Examination) automatically terminates CTOs.[15] Recently, the Consent and Capacity Board passed a policy which potentially compromises rights for CTO clients by ignoring the legislation that states a CTO must be terminated upon reassessment.[16] This is a concern not only because of the lack of discussion on rights but because of the increasing popularity and reliance on CTOs and other types of invasive interventions as a primary response.

In January 2005 and October 2007, the Empowerment Council conducted two focus groups with persons on CTOs.[17] Allowing clients to speak to each other has been beneficial in determining to what extent clients understand the community treatment plan being offered. The focus groups consisted of ten questions looking at the client's perspective of what is required on a CTO, what might happen if they didn't comply and what knowledge clients had about their legal rights. Themes that came up in both groups have raised questions about consent processes, informed lawyers, rights advice, and discussion of self-identified goals. The 2005 focus group included participants with upsetting stories regarding rights violations. The tone of legal mishap was lessened in 2007 as more participants had met with at least one person who spoke to them about their rights, but there still remained limited understanding about how to appeal or complain about services. When inquiring and framing service without legislated coercion as an option, clients were generally surprised that services without force might be a viable option.

As CTOs keep on rolling and are now being utilized as bargaining chips within mental health court and forensic Review Board proceedings, attention must be paid to the seduction CTOs pose as an easy answer to coping with an overall system that is flawed and at this time still oblivious to the diversity, history and cultural aspects of the Mad community.

[*] Lucy Costa is an activist in the Mad Community and an outreach worker with the Empowerment Council.

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[†] Over the years, identity politics within the "Mad" community has grown and changed above and beyond, "patient", "psychiatric survivor" and "consumer". I use various terminology throughout this article to reflect the diversity in labels used by people who self identify as having had contact with the "psychiatric system."

[1] Dreezer and Dreezer Inc., *Report on the Legislated Review of Community Treatment Orders, Required Under Section 33.9 of the Mental Health Act for the Ontario Ministry of Health and Long-Term Care* (December 2005), p 9.

[2] Part 1 of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11.

[3] [1999] 2 S.C.R. 625.

[4] [2003] 1 S.C.R. 722.

[5] Michael Perlin's essay, *You Have Discussed Lepers and Crooks: Sanism in Clinical Teaching*, 9 Clinical Law Review 683–729 (2003), offers a decent analysis about the problem of discriminatory and paternalistic lawyers.

[6] Bill 68 was the bill that initiated CTOs in Ontario.

[7] For more info on the history of the No Force Coalition, please visit www.qsos.ca/qspc/nfc/index.html.

[8] The Empowerment Council is an organization within CAMH providing systemic advocacy to CAMH clients.

[9] The *Making It Happen* report was released in 2002 after consultations with many stakeholders, including psychiatric survivors and consumers.

[10] CAMH and CMHA were both coordinating the administration of CTOs and as such, receiving funding from the Ministry to do so.

[11] In an October Draft of the Ministry of Health Review, the budget for the project was detailed at $281,000.

[12] In one of the items received via a freedom of information request about the CTO review to the Ministry, it was evident that one of the questions posed or suggested to Dreezer and Dreezer was whether they would consider including a consumer on their team.

[13] For reference to these recommendations, please visit the Ontario Federation of Community Mental Health and Addiction Program's website at www.ofcmhap.on.ca/CTO.

[14] The implication being that I should perhaps not have been asking too many questions.

[15] *Supra* note 3 at p. 18.

[16] Consent and Capacity Board, Policy Guideline 3, *Effect of a Form 47 / Order for Examination on a Community Treatment Order* (February 18, 2008).

[17] Access to CTO clients is challenging because there is no way of reaching people without going through the service provider. Privacy restrictions necessitate we rely on letters being sent on our behalf through CMHA or CAMH mailings.

PROTECTIONS FOR PATIENTS ON COMMUNITY TREATMENT ORDERS

Richard L. O'Reilly* and John E. Gray**

Legal statutes that support mandatory outpatient treatment for individuals with mental illness who meet specific criteria have been introduced in many western jurisdictions. There are different models of, and different names for, these types of statutes. In the United States, mandatory outpatient treatment is usually court ordered and generally known as outpatient committal whereas in Australia, Canada and Scotland, it is typically physician initiated and known as a community treatment order.[1] In this article, we will use the term community treatment order (CTO) to describe any form of mandatory outpatient treatment for individuals with mental illness who are not involved with the criminal justice system.

While there is an extensive body of literature addressing the effectiveness of CTOs and ethical issues associated with their use, less has been written about optimal legal procedures to provide protection for individuals placed on CTOs. This article describes protections for individuals on CTOs which we believe should be available in all jurisdictions. We will draw on examples of protections from the legislation of various international jurisdictions, including Ontario, and cite evidence from research literature that supports the use of these protections.

We suggest that three important principles should guide legislators in establishing protections for individuals on CTOs. Firstly, the CTO should be the least restrictive alternative that is appropriate for the individual. Secondly, the protections for a person on a CTO should parallel those for an involuntary patient in a hospital unless there is a clear reason for not doing so. Finally, the protections must not unnecessarily delay or prevent the provision of treatment. In theory, all manner of protections could be provided in a legislative schema but these protections must be balanced against the need to ensure that individuals receive the necessary treatment for their illness.

Protections are included in various parts of the legal schema for CTOs as they are in comparable inpatient committal laws. These protections include specific criteria for being placed on a CTO, mandated oversight by physicians, procedures associated with the consequences of non-compliance with the CTO and review and appeal processes. CTO legislation may also place limits on the types of treatment and supervision that can be provided under a CTO.

The statutory criteria for CTOs almost always contain specific descriptors that are designed to limit the use of CTOs to appropriate patients. International jurisdictions have adopted quite different approaches to formulating these criteria.[2,3] Almost all jurisdictions have criteria that limit the use of CTOs to patients who pose a risk to harm themselves or others. However, international jurisdictions differ on whether or not they also restrict CTOs to individuals who lack capacity to consent to treatment, or restrict their use to individuals who have had previous psychiatric hospitalization.

In most North American jurisdictions, only an individual who is incapable of consenting to treatment can be placed on a CTO, whereas in Australia, this is not the case. Ontario has an unusual hybrid system that allows a capable person to be placed on a CTO but only if the person agrees.[4]

The downside of requiring treatment incapacity as a criterion for being placed on a CTO is that many individuals who might benefit from being on a treatment order have fluctuating capacity to consent to treatment. A potential solution to the problem of fluctuating capacity, that would still preserve the requirement for incapacity, is to use a more flexible *substantially impaired* capacity test.[5] A person who lacks the capacity to consent to treatment much of the time would be considered to have substantially impaired capacity and thus, sustained treatment could be authorized.

Four of the five Canadian provinces that use CTOs – Newfoundland and Labrador, Nova Scotia, Ontario and Saskatchewan[6] – require recent prior psychiatric hospitalization for a patient to be placed on a treatment order. In Ontario, the requirement is that the person has been hospitalized for 30 days or has had two admissions in the previous three years. The Ontario legislation does not require that this prior hospitalization be involuntary, whereas the other provinces do. In contrast, a person may qualify for a CTO in Alberta by a number of alternative routes, such as: previous involuntary hospitalization; previous detention in a custodial institution; or the exhibition of a pattern of repetitive behaviour that indicates they are likely to cause harm or deteriorate while living in the community.[7]

The requirement of prior hospitalization restricts, to some extent, the use of CTO to that group of individuals who have had frequent recent hospitalization – the so-called revolving door patients. However, it also prevents the use of CTOs for other individuals who could benefit from being placed on an order. For example, individuals with mental illness who are being released from jail often fail to meet the prior hospitalization requirements because they have been in jail for most or all of the designated period. The numbers of individuals with serious mental illness in our jails has grown as the availability of psychiatric beds has declined[8] and imprisonment is often the consequence of relatively minor offences that are likely behavioural consequences of untreated mental illness.[9] Thus, the prior hospitalization requirement poses a barrier to the provision of treatment and supervision of a vulnerable population. As noted above, Alberta has crafted their CTO legislation to ensure that requirement for prior hospitalization would not apply to individuals who have recently been in jail.

Furthermore, the prior hospitalization requirement prevents physicians from using the least restrictive alternative. Legislation in Ontario, and other Canadian jurisdictions, requires that an individual meet the inpatient committal criteria in order to be placed on a CTO. Thus, placement on a CTO usually has the effect of diverting the individual from compulsory inpatient care to compulsory care in less restrictive community settings. A requirement for recent hospitalization thus forces physicians to hospitalize patients who may be manageable in the community and may perversely encourage physicians to keep patients in hospital longer than necessary so that they meet the hospitalization requirements. In contrast, the New Zealand legislation states that…"the Court shall make a community treatment order unless the court considers that the patient cannot be treated adequately as an outpatient, in which case the Court shall make an in-patient order."[10] This approach is more consistent with the principle of using the least restrictive alternative.

Legislative schema can set minimum expectations for clinical oversight through requirements for the number, type and frequency of physician review. For example, in Saskatchewan, two physicians must agree that an individual should be placed on a CTO and must sign the initial CTO and all renewals. In contrast, in Ontario, only one physician is required to sign the initial CTO and all renewals. The requirement for a second physician to assess and confirm an individual's suitability for a CTO is an important protection. Occasionally a physician may overestimate risk or be unable to see a therapeutic option that could avoid coercive treatment. Reducing the chances of idiosyncratic decision-making is the reason why all Canadian jurisdictions require that two physicians complete the forms for inpatient committal.

It could be argued that because a CTO is less restrictive than being involuntarily hospitalized the initiation of a CTO by one physician is sufficient. However, we note that a person living in the community has contact with fewer clinicians than an inpatient and therefore requires at least the same level of clinical oversight at the initiation of the CTO.

While we support the requirement for two physicians to initiate a CTO, we recommend against using two physicians to assess the patient before subsequent renewals. It is difficult to arrange for two physicians to assess a person in a community setting within a short time period and this requirement was noted as a barrier to the use of CTOs in a survey of psychiatrists in Saskatchewan.[11]

Here again it is instructive to compare procedures for CTOs with those for inpatient committal. While jurisdictions require two physicians to initiate inpatient committal, most require only one physician to sign subsequent renewal certificates. It is difficult to see why the requirement for CTOs should be *higher* than that for inpatient committal.

Jurisdictions where CTOs are initiated by a physician vary in whether they require that physician to be a psychiatrist. Ontario allows non-psychiatric physicians to initiate and renew CTOs provided the physician is on the staff of a psychiatric facility or otherwise practices in the area of mental health. CTO legislation in all Canadian provinces stipulates that services necessary to support the CTO must be available to the patient in the community. As CTOs are used for individuals who have a severe mental illness that has not been manageable in the community using a less coercive approach, it would seem that clinical input from a psychiatrist is a *necessary service*.

Insisting on the involvement of a psychiatrist could prevent individuals in remote areas, where they have access to a family physician but not a psychiatrist, from being placed on a CTO. At a minimum, we suggest that the requirement be that a non-psychiatrist could renew a CTO "in consultation with a psychiatrist." This would ensure regular discussion between a family physician and psychiatrist as to the status of the patient, current and future treatment and the propriety of renewing the CTO. This is the approach adopted by Alberta.[12]

The duration of CTOs varies between jurisdictions.[13] In Canadian jurisdictions, apart from Saskatchewan, it is six months. In Saskatchewan, a CTO must be renewed every three months. There was broad consensus amongst stakeholders in Saskatchewan that the requirement to renew a CTO every three months was unnecessarily burdensome and prevented the appropriate use of CTOs.[14] Research from North Carolina indicates that most of the clinical benefits from using CTOs are not apparent until a person had been on the order for at least six months[15] which supports using six months as the renewal period.

The provision of rights advice is an essential protection for an individual on a CTO. In Ontario, the majority of rights advice is provided by the Psychiatric Patient Advocate Office, an organization that is independent of physicians and hospitals. It is often more difficult to provide rights advice to an individual living outside of hospital because of problems contacting the person or lengthy travel necessary for face-to-face meetings. Thus, some flexibility, such as allowing the provision of rights advice by telephone, may be necessary.

Individuals who are compelled to follow a programme of treatment and supervision in the community must have access to an independent legal review of this decision. Some commentators have questioned whether a mandatory review should take place at the time of the initial CTO.[16] A mandatory initial review would place a heavy burden on clinicians and, as previously noted, bureaucratic burden is a significant factor deterring physicians from placing individuals on CTOs who would benefit from their use.[17,18] It would be difficult to support mandatory review for the initiation and the renewal of each CTO in situations where a jurisdiction's inpatient committal procedures do not require a similar mandatory review.

Many jurisdictions have opted for a mandatory review at the end of one year, which often mirrors the jurisdiction's requirement for review of inpatient committal. An annual review is especially important when the person is living in the community and may have no contact with a rights adviser or with clinicians apart from their own physician. Parenthetically, we note a marked change in the last 40 years in that the potential for abuse of rights now appears greater outside of institutions than within their walls partly because of the increased scrutiny afforded by hospital based rights advisers and patient advocates.

In most jurisdictions an individual is limited to one appeal per issuance of a CTO. This limit is important to prevent a patient from making serial appeals, which absorb a clinician's time and limit the care that clinicians can provide for other patients.

Legal representation should be available for patients on a CTO who are challenging the order before a review board or court. As is the case with decisions concerning civil commitment patients on CTOs should also be able to appeal the decisions of any review board to the Courts.

Jurisdictions have adopted two different approaches with respect to the powers available to clinicians under CTOs. Early legislative schemes tended to specify the powers available to clinicians under the legislation while "second generation" statutes require the preparation of an individual statutory treatment plan for that patient. The pros and cons of these different approaches have been discussed elsewhere.[19]

The requirement to draw up an additional plan increases the administrative burden imposed on clinicians, but enhances the clinician's sense of obligation to provide the treatment, and provides an opportunity for negotiation between the clinician, the patient and other interested parties. By not specifying the powers, the community treatment plan leaves vague the question of what clinicians can or cannot do. There is, however, a general consensus that forced treatment in non-clinical community settings should not be permitted for patients on a CTO.

Typically, a CTO includes the power to have a person conveyed to a hospital for assessment if the person defaults on the conditions of the CTO. In Ontario and other provinces, before a person is returned for assessment, the physician must have made reasonable efforts to locate the person, inform the person of the requirement to comply with the CTO and the consequences of non-compliance, and, if appropriate, provided assistance to comply. The Ontario approach appears to be reasonable although it is important to note that in some cases when the patient becomes non-compliant, he or she leaves the locality or refuses to interact with clinicians. Thus, the requirement on the physician should be that they have made reasonable efforts and not that they have actually spoken to the patient.

Finally, an important issue is whether returning a patient for assessment voids the CTO. The Ontario legislation is unclear as it describes three options to the physician following assessment: hospitalize on a committal order; discharge from the CTO; or issue a new CTO. It does not mention other options such as admission as a voluntary patient. Importantly, the statute does not say if a patient can or cannot continue on the same CTO. We recommend that a physician should have the option of admitting the patient as an involuntary patient without voiding the CTO, or allowing the patient to return to the community on the same CTO. In some circumstances, an individual on a CTO may not have understood the requirements and may be willing to adhere to the requirements following clarification. Here again, the importance of limiting the unnecessary bureaucratic burden on the clinicians is important. If a jurisdiction supports the use of CTOs, it should try to ensure that clinicians spend their time providing treatment under CTOs rather than on repetitive paperwork. Alberta and Newfoundland and Labrador have adopted a practical approach where a person may be admitted to hospital for up to 72 hours on the authority of the CTO, which is not voided, so that they may be discharged on the same or a modified CTO.[20]

CTO statutes should support the provision of treatment in the least restrictive environment appropriate for the patient. When statutes are based on this principle we should not place unnecessary administrative tasks on clinicians. Administrative burden discourages clinicians from using CTOs and thus prevents treatment being provided in the least restrictive environment. Protection of rights for patients on CTOs logically should be based on the jurisdictions inpatient committal procedures. However, we have argued that for some issues, notably the duration of a CTO, frequency of review and administration of rights advice some variation from the inpatient protocols is necessary.

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PRIMARY CARE AND MENTAL HEALTH SERVICES

Pamela Hines*

This article charts the journey experienced by the Canadian Mental Health Association, Windsor-Essex County Branch (CMHA-WECB) to seek a solution for access to primary care for persons who experience mental illness.

Windsor-Essex is an under-serviced area for family physicians and psychiatrists. CMHA-WECB became concerned that at least 40% of individuals having a mental illness and being discharged from acute care did not have access to primary health care. While the general population were having difficulty obtaining a family physician, there was adverse selection for persons having a mental illness. This segment of the population was more complex, took more time and physicians did not have the supports they required to serve them adequately. Consumers were going without primary care or accessing more costly alternatives such as emergency departments.

Following a strategic planning process in 1998, CMHA-WECB formed a community committee to explore how we could establish linkages with the primary care sector to improve access for persons having a mental illness. A literature review was conducted reaffirming the experience in Windsor-Essex.

The literature suggests that existing models of primary health care might not effectively serve people living with a persistent mental illness. Medical problems in this population have a higher risk of not being treated than similar problems in persons in the general population.[1]

Primary health care practitioners have difficulty finding mental health support for their patients. Lack of sufficient information about mental health agencies and resources in the community create barriers for family physicians seeking to refer patients.[2] This affects whether or not appropriate referrals are made.[3] Other problems include:

- Difficulty in accessing psychiatric backup, advice or consultation, resulting in mental health patients failing to receive needed services. Lack of psychiatric consultation and backup preventing the provision of quality care to persons with a mental illness.[4]
- The fast paced environment in which family practitioners work. Appointments are brief and problems are handled concurrently. This model

of practice is not conducive to the treatment of persons with a mental health issue.[5]

Therefore, primary health care services may not be ideal to address mental health issues due to a lack of understanding and ability to communicate with the seriously mentally ill population.

Lack of accessible primary health care is common in many areas of Ontario and Canada. People having a mental illness experience even greater difficulties accessing primary health care due to stigma and the perception that their care will require more time and as require referral to services that are limited or unavailable. In addition, some clients are isolated, and are unable or unwilling to access traditional health services.[6]

Research indicates that medical problems for individuals having a mental illness have a higher risk of not being treated.

Given the research findings, a member of the CMHA-WECB newly formed committee suggested that the Branch apply for a community health centre. During the process of conducting a community needs assessment, we had the opportunity to apply for funding for a Nurse Practitioner. The committee and the Board of Directors supported the proposal and it was submitted in 1999 and received approval on March 7, 2000. The first nurse practitioner was hired in October 2000 and the Branch was in the business of providing primary care with the support of a family physician.

The following are some case examples illustrative of improved health outcomes based on primary health care/ mental health services access at CMHA-WECB.

Case Example 1

A 35-year old male with schizophrenia attended the clinic for assessment of exacerbation of auditory hallucinations. Upon asking him how he was feeling physically, he admitted to an occasional fleeting sharp pain in his left ear. On assessment, his ear canals were found to be red, swollen almost to occlusion with yellow fluid draining from them. A typical individual would have agonized about headache or "ear pain." In this individual, the physical illness exacerbated a psychiatric response in addition to the physical problem.

Case Example 2

A 58-year old female attended the clinic with severe depression. She had no regular health care provider and had been going from clinic to clinic for medication. A full physical was completed revealing a large tumour in one breast. She was treated immediately with surgery for breast cancer and the disease did not spread.

Case Example 3

A 50-year old female with schizophrenia experienced recurrent urinary tract infections. When the infection started it exacerbated her psychiatric symptoms. Prompt assessment and treatment for the urinary tract infection returned her to baseline and improved her physical and mental health status.

While CMHA-WECB started with only one Nurse Practitioner and a consulting Family Practitioner in October, 2000, we expanded to a community health centre as a satellite of a local community health centre, the Teen Health Centre in 2005. The complement of practitioners now includes two full time equivalent Family Practitioners, one Nurse Practitioner, one Nurse, two Therapists, one Dietician and one Health Promotion Specialist. There is also an allocation for a chiropodist which has not been filled due to space limitations. Several positions including two Nurse Practitioners, one Psychologist and Psychiatric services add to this complement of professionals who collaborate with all mental health providers at the Branch.

From the initial implementation of the program, the services were provided in whatever space was available, which posed considerable limitations. As of April 18, 2008, the satellite community health centre moved into a newly renovated space at the Branch. This will provide a much more welcoming and comfortable space for the people accessing services and the staff providing them. It will also allow us to recruit a part-time chiropodist to provide much needed specialized foot care to our population.

This is a relatively new program and we continue to seek innovative ways to incorporate best practice to improve the shared care model of primary care and mental health services. City Centre Health Care, in collaboration with the Erie St. Clair LHIN, Sandwich Community Health Centre, Teen Health Centre are participating in a program review of the community health centres. The main objectives of this review are to realign community health centre resources and processes and to create a system that will focus on delivering sustainable, integrated and coordinated services that meet the needs of the local population.

This is an exciting initiative that is not only an opportunity to access primary care for people experiencing mental illness, but it also integrates primary and mental health services in a shared care model.

The program has increased access, prevented use of more costly and inappropriate services, improved the client experience and provided an advocacy tool to promote integrated care. Considerable interest has been expressed about this model and the Branch has provided workshops at several conferences including the World Federation for Mental Health Biannual Congress in Melbourne, Australia in February 2003.

We are proud to report that Bonnie Myslik, the program's first Nurse Practitioner, was the recipient for the Marjorie Hiscott Keyes Award at the Canadian Mental Health National Conference held in Ottawa on November 18, 2002.

More recently, the Ontario Medical Society recognized the innovation of the program and increased awareness of integrated mental health and primary care by honouring Pamela Hines, CEO, at their 120th Anniversary on May 3, 2008 with their Centennial Award. This was a welcome reaffirmation of the growing awareness of the need for shared mental health care by the medical community.

This experience demonstrates the need to examine established models of health care delivery in the light of the needs of persons with a mental illness. Interprofessional collaboration enriched the experience of all those involved in the clinic. In the future, it is our hope that interprofessional education and training of all providers will result in better understanding, improved patient care and the reduction of stigma and discrimination for clients living with mental health problems, as both mental and physical health care are critical to the well-being of everyone.

*Pamela Hines, M.S.W., is Chief Executive Officer, Canadian Mental Health Association, Windsor-Essex County Branch.

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3 *Ibid.*

4 *Supra* note 1.

5 deGruy, F.V. (1999). The Primary care provider's view. New Directions for Mental Health Services, 81, 33-39.

6 *Supra* note 1.

ACCESS TO SERVICES FOR INDIVIDUALS WITH MENTAL ILLNESS AND ADDICTIONS – A FAMILY STORY

Claire McConnell*

My personal experience of our mental health and addictions system has been gained through my teenage daughter's recent painful struggles with substance abuse and mental illness, and our family's associated journey. As someone who has worked in this system for 27 years, I thought I knew how it functioned, and held some optimism about the work being done. I was proud to be associated with a mental health and addictions system that was prepared to tackle very difficult issues. However, my experiences as a family member, and now as a newly diagnosed consumer, have profoundly changed my thinking.

After reflecting on the journey that we have all been on over the last year, I see addiction as being like a pebble dropping into a lake – it creates ripples, which spread across the lake in ever increasing circles and affect the whole surface of the water. Our family is like that lake, with the ripples actually spreading further than our immediate family and taking in both extended family and friends.

We discovered the truth about our beautiful, brilliant daughter, who I will refer to here as "R" (a straight A student, superb athlete and scholarship winner) in December 2006, from a good friend who was, unbeknownst to me, working therapeutically with R on her addiction. He said "she is safe but you have to sit down because I have some things to tell you." We listened with a mounting sense of disbelief, shock and horror. She had been using drugs and alcohol for five years? She had been using some drugs daily for more than a year? How could this be possible? Having worked in this field for so long, I felt that my whole world was built on lies: my parenting; my perception of my daughter versus the reality; and my work. It felt as if I were standing in the rubble of my life, with dust in my eyes, unable to see anything but knowing that everything was changed irrevocably. R told me very early on "this is not your fault" but of course I did not believe her.

She needed immediate long-term residential addiction treatment, but there were only six funded beds for transitional age females in Ontario at Alwood, near Ottawa. Their wait list was long. They turn down 75% of referrals, due to lack of capacity. This is not a gender-specific program; both sexes attend certain groups together. Young women who have experienced trauma at the hands of a male usually cannot tolerate doing their therapeutic work in the presence of males. Thus, there is no appropriate long-term youth residential program for this group of females in Ontario. Non-residential services, whilst entirely appropriate for some clients, cannot serve youth who need to be in a structured residential setting with their peer group, away from the environments in which they used substances.

As those working with R felt that she would not live for much longer without treatment, we decided to send her to Portage, a long-established national program for youth, which treats males and females separately. In New Brunswick, Quebec and British Columbia, Portage receives funding from the respective provincial Ministries of Health. In Ontario, it does not (although it receives funding for youth justice beds, and also from the Children's Aid Society). Thus, we had to find $158 per day for the cost of her treatment so that she remain alive and move towards recovery.

Last May she graduated from the program and returned home. However, the journey was by no means over. Despite everyone's best efforts, she slid downhill and within two weeks had to be hospitalized. Her new psychiatrist gently informed us that R had been suffering from depression and anxiety since early adolescence. The substance abuse was a form of self-medicating. Again, the guilt surfaced. How could I not have known this? What kind of parent was I? What about my training as a therapist? Was I completely stupid?

My personal experience interacting with the system, of which I had previously seen myself as an integral part, was an interesting, albeit very stressful, one. Those trying to help R and who knew me in a professional capacity tended to defer to me, and minimize the significant stress I was under. Those who did not know me professionally patronized me and talked down to me. Families find themselves in a terrible bind. They are often ignored and not given the information and support they need to cope. In frustration (and I speak from personal experience), family members may display some anger with their child's caregivers, even though it is expressed with fear and trepidation – one does not wish to alienate those who are trying to help. Seeing this anger, caregivers may label family members as either hysterical or controlling – and so the spiral escalates. We were often given mixed messages – on the one hand, I was told to "take a back seat" and "trust the process." On the other hand, we were the ones with whom R lived when she left hospital, and we were given no tools with which to cope. I was also the first person to whom professionals turned when she was not doing well. This is no reflection on the skill, caring and competence of the many wonderful people who have helped us all through this terrible time. However, the shared service approach to serving the needs of individuals with multiple and complex needs does not exist, even though I think many professionals believe that it does. So did I, until my personal experience completely changed my perspective. R's psychiatrist, responding to my extreme frustration, said to me "I think we put a huge burden on family members, and don't give them the tools to cope – and you are articulating that clearly to us." However, the toll this journey has taken on me has been high; I was recently diagnosed with a major depressive episode – and I am a very calm, grounded, competent woman. But with enough stress, even the strongest tree breaks.

To add insult to injury, there is no way for us to be reimbursed by the government for the costs of R's treatment – about $60,000 to date. No reimbursement exists for within province private treatment. The only reimbursement for out of province and out of country treatment is through Ontario Health Insurance Plan (OHIP) funds. If the facility is within Canada, it has to meet the definition of a hospital under the *Canada Health Act*.[1] If it is in the U.S., the facility has to meet the definition of an accredited health facility. R could not cross the border to the U.S., as she had a pending criminal drug possession charge. Thus, we had no options other than to pay for her treatment or watch her die. We have put in an appeal to the Health Service Appeal and Review Board, but this is a long, slow process. We will lose our appeal, because the role of the Board is to interpret the legislation, not to rule on the merits of a case. After that, we will go to the Ombudsman – I will not give up this battle.

In Ontario, for the majority who cannot access the few existing publicly funded residential treatment beds, there is a three tier system, with three separate classes of clients. The first are the rich. They take their child to a private therapist, who knows about the policy for out of country treatment and sends them to their family doctor to complete the forms for OHIP approval. If OHIP turns them down, the families hire a lawyer who takes OHIP to court to fight the decision on the grounds that OHIP has a "duty to pay."

The most popular facilities to which the children are referred are "wilderness camps" (similar to the "boot camp" model). OHIP can pay hundreds of thousands of dollars for this so-called "treatment" (for example, Hazeldon charges $32,000 for the first month) – and yet we cannot get reimbursed for R's much more appropriate and humane treatment here. Surely taxpayers' dollars being sent to U.S. "boot camps" could be much more appropriately used to address the huge service gap in Ontario by setting up more treatment facilities here? Not only would that help with the very long waiting lists for treatment, it would also provide employment for Ontario citizens.

Furthermore, I question the clinical validity of "treating" a child thousands of miles from home, and then expecting that they will be able to reintegrate into their home environment. If their therapists are far removed from the local service providers, I cannot see how they can build the necessary linkages between service providers that are so vital during the time of transition home. And this time is critical, as our family has learned the hard way.

The second class of clients are families like us, who are not wealthy enough to pay for lawyers to fight OHIP, and who may not want to send their children to the U.S. Some of this group of parents end up taking out second mortgages on their homes, and assume a huge financial burden.

The third class of clients are the marginalized and impoverished, who have no hope of paying for treatment anywhere and have to wait months, often in intolerable situations. I know of one single parent whose son is using crystal meth; he lives at home and regularly defecates all over the house. All she can do is wait, as there are no services that can take him at this time.

My hope is that changes can be made to our system in order to ensure that parents and children experiencing substance abuse problems or a concurrent disorder can get timely, clinically appropriate services as close to home as possible, without having to take out a second mortgage to pay for them. In a country where universal health care is a sacred value, this is not too much to ask.

[*] Claire McConnell is a mental health and addictions professional, who has spent more than twenty five years working in the system – first as a front line staff, then as a manager in progressively senior positions, and most recently as a systems planner. Since her daughter's experience, she has become a passionate advocate for systemic change and for the need to urgently create more treatment beds for youth.

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[1] R.S., 1985, C. C-6.

WHAT DOES RECOVERY FROM EATING DISORDERS MEAN?

Mary Kaye Lucier[*]

Eating disorders are thought of as starving away, stuffing down, and throwing up feelings that have gone unrecognised and needs that have gone unmet. Recovery does not only occur in reference to an organization's success rate, which is often written about in the literature, but recovery is an individual's experience of change over time related to thoughts, feelings and behaviours associated with eating weight and shape. Recovery is applying or using different coping strategies to identify feelings, and meet needs, other than focussing on food weight and shape.

One of the first steps towards recovery is creating an idea or definition of what it would mean to live without an eating disorder; or, to reduce the reliance on eating disorders for relief from painful or difficult memories or daily experiences. This definition or idea can spring from treatment or other challenges to the disorders. For some, it may mean improving the quality of life such that hospitalization is avoided; for others, it may mean complete symptom cessation; and still for some others, it may mean delaying or doing something different rather than engaging in the eating disorder in the moment.

The recovery process takes time, commitment, practice and a support network of knowledgeable people about eating disorders. Rarely does it happen spontaneously, or without a support network. It is difficult, and many report frustration, impatience, and feelings of ambivalence towards recovery. Persons with eating disorders may expect to have many setbacks along the way, and attention needs to be paid to how and when the setbacks occur.

There is a self-perpetuating nature to eating disorders that are as mysterious as the drive towards recovery. The dieting craze, the prejudice against and hatred of persons who are above average size, and identifying with the stereotypical gender based ideal are some of these self-perpetuating factors. What is mysterious is that not everyone has an eating disorder, despite the fact that the same social pressures affect us all. Individuals in recovery are beginning to identify, examine, chart, and express what these factors mean to them. Some of the questions they might ask themselves are: when did I go on my first diet, what are my experiences with sizism, how has my gender affected my development and how has this translated into my eating experiences from early childhood to now? Pondering the answers to these questions may help to formulate an idea or definition of recovery:

- to eat a healthy diet;
- to accept your more natural size;
- to allow yourself to express your feelings, and meet your needs according to your own experiences; and
- to reclaim your right to a high self esteem.

Recovery is possible, and adopting realistic expectations is essential, for society does not always reward these behaviours. Recovery does not promise acceptance from society, but recovery is when there is acceptance of self. In this Bulimia Anorexia Nervosa Association's 25th year of offering services to the community, we reflect back on our origins from tragedy, to triumph. The Bulimia Anorexia Nervosa Association would like to honour all of our clients, friends, families, board, staff and supporters by encouraging them to attend our conference on eating disorders September 9 – 11, 2008 in Windsor Ontario.

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FROM OPPRESSION TO HOPE: ADVOCACY FOR VOICE AND CHOICE THE HISTORY OF PATIENT COUNCILS AND THE ONTARIO ASSOCIATION OF PATIENT COUNCILS IN ONTARIO – YESTERDAY, TODAY AND TOMORROW

Theresa Claxton[**]

Patient Councils provide a voice for consumer/survivors[1] in the institutional environment where people are typically at their most powerless. They advocate for improvements in quality of care and patient safety, as well as respect for patients' rights under the law. Patient Councils are based on principles of empowerment, peer advocacy and peer support.

One of the first references to Patient Councils comes from the archives of what is now known as the Centre for Addiction and Mental Health, Queen Street site, in Toronto. In a memo dated October 22, 1958, the Superintendent of the Ontario Hospital, announced the formation of a Patients' Council to all patients and staff. Elections were held and "the first meeting of the Council was held on November 26, 1958."[2]

One of the next steps towards consumer/survivor empowerment in psychiatry came about in 1989 when the first Canada wide conference, *Our Turn*, was held in Montreal for people who had experienced the receiving end of mental health services.

One speaker at the conference, Hans Wiegant, described the experience of Dutch Patient Councils and the formation in 1980 of the Patients' Councils Foundation in Holland. These initiatives were government sponsored organizations of current and ex-patients who represented the interests and rights of people inside psychiatric institutions.

As a result of the consciousness raising by their international peers, the people who attended the conference came to call themselves psychiatric survivors.

Back in Ontario, people began to get organized. An initial meeting was held to discuss the idea of Patient Councils in Ontario. The Ministry of Health and Long-Term Care was involved and provided funding for this initiative. The following is a non-exhaustive list of those people who attended this meeting: Irit Shimrat and Randy Pritchard of the Ontario Psychiatric Survivors Alliance; Pat Capponi of the Leadership Project; Jennifer Chambers representing an as yet unnamed group of patients and survivors at the Queen Street Mental Health Centre); Dave Stewart from Kingston; staff from both the Queen Street Mental Health Centre and Kingston Psychiatric Hospital; Howard Danson, representative of what was then the institutional sector of the Ministry of Health; and Mary Beth Valentine of the Psychiatric Patient Advocate Office. Many other meetings followed and membership shifted. The Ministry of Health did not keep its commitment to have the steering committee chaired by a psychiatric survivor, resulting in the loss of some strong voices from the project.

A decision was reached to fund pilot Patient Council projects at the psychiatric hospitals in Kingston and Toronto, and soon after, in Penetanguishene. The goal was to maximize the voice of consumer-survivors' and to have consumer-survivors positioned as a full and equal partners at all levels of mental health service provision, planning, evaluation and systemic advocacy.

Tensions existed throughout the founding process and it is still felt by Patient Councils today. The greatest conflict of values arose with respect to the support for institutional interests versus the desire to be an independent and honest voice for people in the psychiatric system.

Ultimately it was agreed that Patient Councils would be formed by bringing together psychiatric patients/ex-patients/survivors at each provincial psychiatric hospital to form a membership that would elect a Board and hire their own staff. Everyone involved with the Councils would be people who had personal experience with the psychiatric system. The Ministry of Health and Long-Term Care would direct the hospitals to allocate a portion of their budget to fund the Patient Councils. On this basis, the Councils were born – first Kingston, then Queen Street, in 1992. There was tremendous enthusiasm for greater user involvement and Patient Councils became established in all of the former and current provincial psychiatric hospitals, as well as one Schedule 1 facility.

As the Ministry of Health and Long-Term Care began to divest the governance of the former provincial psychiatric hospitals to Schedule 1 facilities, Patient Councils struggled to remain autonomous with a genuine voice while maintaining and improving their funding status. Autonomy is critical – Patient Councils do not become an agent of the facility but rather have an arms-length relationship with the service provider.

Despite these challenges, the principles underlying Patient Councils, as wells as patient-centered care is accepted and widely utilized. In their efforts to secure ongoing input and meaningful involvement from clients and patients, and to remain accountable to stakeholders, the work of Patient Councils have been welcomed as part of the comprehensive and integrated mental health program at some hospitals. Patient Councils do not duplicate the work of other programs or services but instead complement and supplement the work of staff, service providers and advocates through networking and referrals. This allows patients to have a choice in who provides them with service and options for issue identification and resolution.

Today, Patient Councils: ensure the voice of consumer/survivors is heard in the planning, delivery and evaluation of the mental health system at all levels; advocate for and ensure the rights and entitlements of individuals are protected; promote recovery; provide immediate support to peers; engage in individual and systemic advocacy; provide education and training for all stakeholders; engage in community development; conduct research; participate in the design, implementation and provision of stigma reduction and public education programs; and provide social opportunities for peers.

Patient Councils provide their peers with the knowledge and comfort of knowing that there are people within the hospital that have had the same or similar experiences and that they can approach them to talk. Support is not based on psychiatric models and diagnostic criteria. It is about understanding another person's situation, through empathy and shared emotional experiences. This can be incredibly powerful in helping us to grow, learn from each other, and challenge each other beyond what we thought we were capable of.

Ontario Association of Patient Councils

The Ontario Association of Patient Councils (OAPC) was formed in 1993 to provide a coordinated network of representatives from Patient Councils in psychiatric facilities, to share challenges and knowledge and to provide a united and clear voice to address the issues of critical importance to Patient Councils and consumer/survivors.

Our goal is to work together with all stakeholders to improve the quality of the mental health and addiction care systems and to provide a collective voice in addressing systemic issues – whether it be raising awareness of the importance of Patient Councils and the inclusion of the consumer/survivor voice, pushing for adequate funding for mental health treatment and more research into mental illness and addiction, getting much needed help with housing, employment and education, promoting recovery, ending stigma and discrimination, addressing patient safety. The OAPC recognizes that the empowerment of people in psychiatry is a crucial issue in mental health, as "people who have been devalued and disempowered can only start to be restored to full citizenship, if the power imbalance between users and providers is redressed." Citizenship is central as a goal and as a lens for decision-making.

As we look back, we realize we still have much work to do. Patient Councils have yet to be established in all hospitals with psychiatric beds. All Patient Councils need to be treated as essential services to our community and must be fully funded, receiving a fair share of funding and resources. Patient Councils need to be fully autonomous to be able to provide service to their respective constituencies.

As we face the future, we celebrate how far our movement has come since a disparate group of patients, ex-patients and advocates came together to ensure that mental health and addiction services are directed and accountable to the people they serve. We celebrate coming together as a group to be inspired and energized to ensure a future of effective and inclusive advocacy. We continue to strive for our ultimate vision of a society that embraces the dignity, integrity, strength and self-determination of all citizens living with mental health and/or addiction problems.

[*] Theresa Claxton is a mental health consumer and peer advocate. She currently sits as chair of the Ontario Association of Patient Councils and co-chair of the North York General Hospital Participants' Council (Toronto).

[†] Sincere thanks to Jennifer Chambers, Facilitator, Empowerment Council, for her contributions to this article.

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[1] The Ontario Association of Patient Councils uses people-first language whenever possible. For example, "people with mental illness," "individuals living with addiction," "our peers", etc. We recognize and respect the fact that not all individuals will identify with these terms and may identify themselves differently. The use of the term "consumer/survivor" is used within this document to positively reflect the principles of self-determination for individuals as they move towards wellness and recovery.

[2] CAMH Archives, Queen Street, John Court, File 28-20.

VOICES FROM THE STREET

Michael Creek[*]

In 2005, the Gerstein Centre, in partnership with the Ontario Council of Alternative Businesses (OCAB), the Parkdale Activity-Recreation Centre (PARC) and the Gerstein Centre developed a pilot project, funded by the City of Toronto, to train twelve individuals who had been homeless and/or experienced mental health issues to become educators on issues of homelessness, poverty and mental health. The project is built on the premise that people who are or have been homeless are vital members of the community and that public perceptions and attitudes toward those experiencing homelessness need to change in order to positive, long-term solutions to be realized.

The Atkinson Foundation became interested in the work of Voices from the Street and agreed to fund it for a further three years to assist in the development and expansion of the project.

Voices from the Street is a collective of individuals who use their personal experiences with homelessness, poverty, mental health issues and life struggles to educate the public and push for change. Members complete a twelve-week training program in public speaking, leadership, conflict resolution, diversity and facilitation. This program allows participants to connect with others who have similar experiences and a desire for change. It also introduces the participants to the issue of public policy to enable them to have an understanding of how policy is developed and how it can be impacted.

We have developed key relationships with various community organizations and individuals in the policy area. Members of Voices from the Street speak to university and college students, medical residents, social service agencies and community groups. They are active on community boards and on committees such as the "25 in 5" poverty reduction project and the City of Toronto's Innovators Council. The speakers can address a wide range of topics from domestic violence, poverty and health to homelessness, mental health, addictions and social inclusion.

My name is Michael Creek and I'm a board member of the Gerstein Centre and a graduate of the Voices from the Street training program. I have recently been appointed to the Board of Directors of the National Anti-Poverty Organization.

I have been on an incredible journey over the last year! It has been filled with personal change, knowledge and self-recovery. I will begin by telling you a little about myself. In 2007, I turned 50, an event that surprised and pleased me. Having been diagnosed with non-Hodgkin's lymphoma (B-cell) cancer at the age of 37, I never expected to reach 50. After receiving chemotherapy, my body was a mess – no hair, my fingernails and toenails fell off, I had lost 80 pounds and I was in very bad shape! I was in remission but left with debilitating side effects of deep vein thrombosis of the right leg and chronic pain from recurring leg ulcers. I was told that I would never work again and my life in poverty began. I managed to get social assistance from the Ontario Disability Support Program (a humiliating experience) and subsidized housing through the municipal housing authority. I isolated myself from friends and family, became more depressed, and retreated from society for 13 years.

I have survived sexual abuse, physical abuse, mental abuse, cancer and mental illness but poverty has been the biggest struggle of my life. There is no powerful pill or magic potion that will help you fight poverty. Poverty oppresses people and their communities. It was my unwanted companion for years and has caused more physical and emotional pain than any other illness I have gone through. Everyday is a struggle when you live in poverty – you become isolated, lonely, and often hungry. Poverty leads to the total degradation of the person. The system is designed in such a fashion that shame and humiliation become the so-called norm.

As with so many psychiatric consumer/survivors, I have come to terms with my mental health history. I respect and try to understand others in my community who share this label and I have found acceptance and understanding in the consumer/survivor community. Now, you may ask yourself how all this happened to me. I was disillusioned by the psychiatric profession and wanted no part of it. This of course, is my choice. In January of 2007, I was visiting my medical doctor after a really bad year of depression, when I saw a poster for Voices from the Street. It was advertising for candidates to train to speak about their experiences of poverty, homelessness, and mental health. I applied and was accepted into the course. I have to admit that I was a little sceptical at first but I kept an open mind, hoping that somehow I could find a way to fight back against many of the systemic problems related to poverty.

At Voices from the Street I learned to accept the truths of my life and to just be myself. I didn't need to blame myself. I learned to express my views through the personal narrative. It was not an easy experience learning to tell my story, and it was heartbreaking and painful to hear others speak of their experiences in life. But, Pat Capponi[1] knew the value of each story and she knew that by being honest with ourselves our lives could change and that we could help to bring about changes in society.

When I did speak, I released years of pent up denial and frustration. I was finally unshackled from the shame of poverty and able to realize that many of my struggles in life were not my fault. Although my battle with depression will be with me forever, my fears and isolation have ended. There will be times of darkness but my exposure to the community of consumer/survivors has had a profound effect on me. I will fight for my rights and for the dignity that we all deserve.

On this journey I have meet the most remarkable people and I've had more eureka moments than the Oprah show will ever have. I've spoken to many individuals and organizations over the past months – from university students to doctors, lawyers, and policy makers. I've been involved in issues concerning housing, welfare, social inclusion, dental care, health care, legal services, mental health and many others involving social justice. I have a voice and I use it whenever I can to speak out on issues that affect me and my communities. I'm not a failed person but someone who has been failed by bad policies.

My life and the lives of many of my friends have changed since taking the training offered by Voices from the Street. We use our knowledge and power to fight for change! We are activists and advocates, but most of all, we are survivors willing to take a stand against injustices in our society. We have taken our stories and our struggles in life and turned to fight for the freedom, security and dignity that we all deserve.

[*] Michael Creek is a member of the Toronto Speakers Bureau: Voices from the Street. He is a director for Ontario on the National Anti-Poverty Organization and he sits as a member of the Board of the Gerstein Crisis Centre in Toronto.

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[1] Pat Capponi is a well-known mental health activist and author or several books.

FROM THE EXCEPTION TO THE EXPECTED: OPDI AND CONSUMER/SURVIVOR ORGANIZATIONS IN ONTARIO TODAY

Joel E. Johnson,[*] Barbara Frampton,[**] Raymond Cheng[†] and Shawn Lauzon[‡]

History

It is hard to imagine that in less than two decades, consumer/survivor organizations and their volunteers, staff, and representatives have evolved into a respected stakeholder at the mental health decision-making tables. That this is happening now at provincial, regional, and local levels is not new. It's therefore worthwhile to revisit how it all came to be.

The development of consumer/survivor organizations was based in the community and drew upon earlier groundbreaking government reform documents such as the *Toward a Shared Direction in Ontario*[1] and *Building Community Support for People*.[2]

It was in 1991 that funding was directed to the original consumer/survivor initiative. With a staff of six (three consumer/survivors and three non-consumers), the Consumer Survivor Development Initiative (CSDI) began its operations. CSDI was designed to tap the skills and knowledge of people who had direct experience in mental health services support and employment opportunities. By June of 1991, 42 programs throughout Ontario had been funded; statistics for 1992 showed that 81 full-time equivalent positions had been created in these projects, with 307 people employed. Three-quarters of this group had been on social assistance prior to this employment, testifying to the effectiveness of what was viewed then as a temporary anti-recessionary measure.[3]

In 1993, CSDI became fully staffed by consumer/survivors. In 1996, the newly-elected government released an additional $23.5 million to enhance community mental health, leading to the formation of 24 additional consumer/survivor groups through the Community Investment Fund. There are now approximately 60 consumer/survivor initiatives in Ontario and each one is unique.

By 1998, CSDI had started up an Advisory Committee that in turn evolved into a Board of Directors. In 2001, CSDI took the necessary steps to incorporate and changed its name to the Ontario Peer Development Initiative (OPDI).

It Works

Consumer/survivor initiatives and peer support organizations are effective. Using the principles of peer support and self-help, the members of these groups share with each other their knowledge and understanding of empowerment, hope, and wellness. Each one of these programs are different because, as needs-based programs, they offer meaningful choices in supports such as self-help groups, wellness and recovery education and training, committee participation, systemic advocacy, and social-recreational activities. For example, patients' councils offer systemic advocacy and peer support programs for consumers and families in general and psychiatric hospital settings while alternative businesses incorporate community development principles into creating meaningful jobs for survivors.

Consumer/survivor organizations do not keep wait lists. People can join anytime, and most activities are at no charge, thus serving to alleviate the pressure on other service providers. As community mental health investments have emerged, including mobile crisis intervention teams and court diversion programs, consumer/survivor organizations, employees, and volunteers find themselves increasingly integrated as valued partners, patient advocates, and key contacts within interrelated systems of care.

The Evidence

Consumer/survivor initiatives and peer support organizations have benefited from participatory action research collaborations over the years. Participation in consumer/survivor initiatives has been directly linked to a reduction in the rate of re-hospitalization, reduced use of mental health services, symptom distress, and improvement in people's quality of life. A partnership between peer support organizations and hospitals to take care of people being discharged from care also has been shown to reduce an estimated $12.2 million worth of hospital days in a group of less than 200 people.[4] These kinds of desirable impacts are consistent with a provincial health care vision that acknowledges that the patient is at the centre of an integrated and results-driven system of community-based care. With their experiential knowledge, grounded in a wellness and recovery-based approach, and backed by evidence-based research, OPDI and consumer/survivor organizations are becoming valued partners.

Voices of Experiential Knowledge

Having firsthand experience of how and why discrimination and social determinants of health such as housing, financial support, and education play important roles in people's mental health is critical to a balanced approach in considering outcomes for the mental health care system. The voices of consumer/survivors within stakeholder discussions and meetings at the provincial government level are a unique blend of high-level policy understanding grounded with grassroots experiences respecting the impact on people who use these services.

Incubators of Individual Recovery

The 2006 *Out of the Shadows at Last* report from the Senate Committee on Mental Health in Canada highlighted many of the defining issues of where mental health policy needs to go, and the importance of where consumer/survivor initiatives fit into the future. The Commission's report stated: "Self-help and peer support groups are the incubators of individual recovery and a key sustaining force behind the broader acceptance of recovery as the guiding principle for all that occurs in the formal system."[5]

Good work has been done but how do we maintain the momentum?

Lifeboats and Lighthouses Leading the Way

Consumer/survivor and peer organizations lead the way in ensuring that a transforming provincial mental health system is person-centred by offering supports based on expressed needs. As such, they have a leading role to play in a health care environment that welcomes diversity, innovation, and attentiveness to democratic decision-making, and are grounded in evidence-based best practices.

As lighthouses, they shine the beacon of hope that is peer support. They also serve with their flashing light to warn of potential problems at hand.

In her remarks to the Policy Forum[6], hosted by the Provincial Mental Health and Addiction Partnership, OPDI's Past President, Barbara Frampton, spoke passionately and vividly for the case that peer support organizations are natural change agents. Her key points were:

- Consumer/survivors do value a mental health system with services and supports, because they ALL serve a unique purpose;
- Each service and support is needed because consumers and survivors need and deserve choice;
- As unique and distinct components of the mental health system, consumer/survivor organizations are necessary – amalgamation or assimilation is NOT an option;
- Partnerships are an option – we need to communicate more and work together on various projects;
- Consumer/survivor organizations can be tugboats or lifeboats, guiding the larger barges (service providers) through areas to get to a common destination;
- Consumer/survivor organizations can help crowded boats (wait lists at hospitals and agencies) by taking on some of their clients and bridging their way to safe ports of harbour; and
- Consumer/survivor organizations have much in the way of experiential expertise as "enablers;" they can be planners, recovery educators, providers, evaluators, peer supporters, governance advisors, and policy leads.

It is not being said that consumer/survivor organizations do not face challenges. They remain under-funded in comparison with the rest of the mental health sector. Volunteers have to overcome barriers to inclusion due to lack of travel subsidies, meeting fees, and reimbursements for accommodation and meals.

Moreover, meaningful participation for consumer/survivors may mean doing things differently. People may work better, for instance, using focus groups and answering surveys. In terms of process, many people prefer a membership-driven, transparent, democratic process that values honesty and open communication.

A Mental Health and Addiction Partnership

In 2007, OPDI was approached and has since accepted a seat at the table with the Mental Health and Addiction Partnership. This Ontario alliance of stakeholders includes Addictions Ontario, Centre for Addiction and Mental Health, Canadian Mental Health Association (Ontario), Ontario Association of Patient Councils, and Ontario Federation of Community Mental Health and Addiction Programs. OPDI has therefore been able to establish a consumer-centred perspective in a respected and productive alliance.

A Provincial Voice That Is Loud and Clear

Over the last 17 years, CSDI has evolved from an unincorporated part of the Ministry of Health and Long-Term Care with a team that provided technical advice to emerging and maturing consumer-driven organizations to the current incorporated OPDI that has a revitalized role within the health care transformation process as a provincial voice for consumer/survivor organizations.

The dynamics of consumer/survivor participation have evolved from the exception to the expected. With our knowledge of peer support, organizational history as consumer/survivor organizations and ongoing development of best practices as autonomous agencies, OPDI looks forward to the future.

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[1] 1987.

[2] Graham Report, 1988.

[3] "Consumer/Survivor Initiatives: A Case Study (1996) Trainor, J., Shepherd, M., Boydell, K., Leff, A., and Crawford, E.

[4] "Therapeutic Relationships: From Hospital to Community" (2002) available at: www.chsrf.ca/final_research/ogc/pdf/forchuk_e.pdf

[5] "Out of the Shadows At Last" (2006), p. 253, available at: www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/rep-e/pdf/rep02may06part1-e.pdf.

[6] Partnership Policy Forum "What does local integration mean for mental health and addictions services?", November 26, 2007.

CONSUMER SURVIVOR EMPOWERMENT AND RECOVERY

Robyn Priest* with input from Mary O'Hagan**

Empowerment and recovery – what do these terms mean? What do they mean for us as consumer survivors and what do they mean for the sector?

Let us start with empowerment. The World Bank defines empowerment as:

> The process of increasing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes. It is the process of increasing the assets and capabilities of individuals or groups to make purposive choices and to transform those choices into desired actions and outcomes. Empowered people have freedom of choice and action. This in turn enables them to better influence the course of their lives and the decisions which affect them. It's about:
>
> - Access to information
> - Inclusion and participation.[1]

Wikipedia defines empowerment as:

> The process through which enables others to gain power, authority and influence over others, institutions or society. Empowerment is probably the totality of the following or similar capabilities:
>
> - Having decision-making power of their own
> - Having access to information and resources for taking proper decision
> - Having a range of options from which you can make choices (not just yes/no, either/or.)
> - Ability to exercise assertiveness in collective decision making
> - Having positive thinking on the ability to make change
> - Ability to learn skills for improving one's personal or group power.
> - Ability to change others' perceptions by democratic means.
> - Involving in the growth process and changes that is never ending and self-initiated
> - Increasing one's positive self-image and overcoming stigma.[2]

This term has been around since the 1960's and yet we still hear people, particularly health care workers, talking about empowering consumer survivors. Can consumer survivors be empowered by someone else or do we need to empower ourselves?

Let's talk now about the term recovery. Recovery as a mental health concept has been around since the early 1990s and yet we still see documents in 2007 that say:

> Recovery is gaining prominence as a guiding principle for mental health services which has evolved from the lived experience of people who use services. It is a concept that has attracted considerable enthusiasm and hope in an area often characterised by disillusionment and defeat. It presents all of us involved in mental health services with the challenge and opportunity to work together and to integrate our various skills and experiences.[3]

Recovery has many definitions. Patricia Deegan, a consumer survivor from the USA, defines recovery in the following way:

> Recovery does not mean cure, it is a hopeful attitude, a way of approaching the day practitioners and carers working with people with mental illness need to:
>
> - See the person as more than the illness
> - What is the person recovering from? (e.g., poverty, trauma, internal stigma, demoralisation)
> - Recovery is a dimension beyond rehabilitation it may involve a kind of transformation
> - Recovery is a unique (individual) journey
> - Insightfulness of problems is not the same as accepting the illness diagnosis
> - Recovery may not mean symptom free.[4]

The New Zealand Mental Health Commission defines recovery as "the ability to live well in the presence or absence of one's mental illness" (or whatever people chose to name their experience).[5]

Ron Coleman, Scottish Consumer Survivor says: "Recovery requires self-confidence, self-esteem, self-awareness, self-acceptance, it is a liberating process, a social process and one in which practitioners need to believe in."[6]

Definitions may be many but the common thread is that it is a unique experience and that the person themselves must define what they believe to be recovery. The question posed here is whether that is truly happening, or have the terms empowerment and recovery now been taken over by others?

As consumer survivors, do we have the say in how we want services to be and what services are actually provided? Have we moved forward significantly in the last 25 years or are we still beholden to the establishment?

A story told by a Canadian consumer survivor was quite frightening if we want to believe that empowerment and recovery is truly occurring. That person told us that in a meeting a quite senior worker, he started lecturing her on the "recovery model" and arguing with her about what recovery is and isn't. At a certain point, she said, "Shit, I must have done it all wrong. Now I have to start all over again." Another story we heard was that of a proposal that discussed offering a recovery oriented service to people with chronic mental illness. How does the concept of recovery fit with the concept of "chronic mental illness"?

In some countries, we have moved people out of large institutions to group homes; in others, we are moving people out of large institutions into single apartments but in areas that are just for people with mental illness that are developed by mental health services (apartments, shops, etc all lived in and worked in by people with mental illness). Does this constitute recovery for someone? Mental health services may argue this is what consumer survivors want but if people have never experienced life within natural diverse communities, how can they make informed choices?

Empowerment and recovery are about self-determination, taking ownership of one's life, having social networks, knowing one's rights and responsibilities, making informed choices, risk taking and interdependence, to name but a few things. Although nobody can empower consumer survivors, or provide recovery, people can support consumer survivor journeys by supporting us to gain the necessary tools.

This paper is not intended to say there has been no movement over the past 25 years because it is clear there has been. Many countries have consumer survivor leaders working on change for the better. What we want/need to see is how we can translate the work of consumer survivor leaders from rhetoric into change at a local level, specifically the mental health service in the rural and remote services, or the area mental health service in the city.

The challenge for the next 25 years is for all consumer survivors and services to be supported to continually challenge themselves, to be at our best and to take risks that allow learning and growth. The challenge is to support each other to have higher expectations of ourselves; that way, we will have higher expectations of all (ourselves, the system and communities).

In 25 years where will we be? Just another member of the diverse communities that we live in, gaining short-term support just like everyone needs at different times in their lives.

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1 www.worldbank.org.
2 http://en.wikipedia.org/wiki/Empowerment.
3 Joint Position Paper – A Common Purpose: Recovery in Future Mental Health Services Care Services Improvement Partnership (CSIP), Royal College of Psychiatrists (RCPysch), Social Care Institute for Excellence (SCIE) May 2007.
4 Ron Coleman, Training Material: Recovery for Middle Managers, 2008.
5 New Zealand Mental Health Commission, 1998. *Blueprint for Mental Health Services in New Zealand: How Things Need To Be.* Wellington: Mental Health Commission.
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THE PROMISE OF A MORE RESPONSIVE MENTAL HEALTH SYSTEM

Laurie Hall*

Twenty-five years. A lot has changed in 25 years – some for the good, some for the worse… and some things, well, they never seem to change. Congratulations to the Psychiatric Patient Advocate Office (PPAO) for 25 years of successful growth and change. As for the mental health system, well, it hasn't changed much.

I have been a survivor for over 27 years and have seen, and in many instances experienced, what has changed during that time. A visit to the hospital is very different now than it was 25 years ago. Medications have changed, some professional approaches have changed, there are fewer beds in the system and more money in the community (but not anywhere near what we were promised when they began to reduce hospital services and said they would move the money into community services). Instead, much of what we have seen added to the community is the latest, newest "best practices" almost always identified by professionals and academics – never survivors. We got "client centered care" and case managers up to the eyeballs (although I never seem to be able to get one for someone who desperately needs one). Then, we got community treatment orders and assertive community treatment teams – at the cost of another several million dollars. The promise that there is one position for a consumer/survivor on each assertive community team, in many cases, was diminished to a half-time position or even eliminated. During this time, government reports were written – increasingly with some input from consumer/survivors and consumer/survivor organizations.

There were very few consumer/survivor organizations 25 years ago – especially any that had funding. Twenty-one years ago, A-WAY Express was created and we often felt very isolated in our voice for change – it was the strong voices of a small number of consumer/survivors that led the way for us. We owe those people and the ones who came before them a huge debt of gratitude.

Over the years, particularly in the early 1990s when the government used anti-recession funding to fund more than 20 consumer/survivor initiatives across the province, the consumer/survivor voice gained momentum. Government reports, such as *Putting People First*, about the future of mental health services cited consumer/survivor initiatives (e.g., peer support, alternative businesses) as an example of a "best practice" for supports in the community.[1] We've read many reports since that one, each one more reflective of the government in power's agenda than what was actually happening in the community or the day to day lives of consumer/survivors.

Less than ten years after *Putting People First*, the conservative Harris government *began to talk about "putting patients first:* - we'd gone from being people to being patients in less than ten years!!

In the 1990's, empowerment was the word of the day, but over time it came to mean less and less as the established system used it to describe anything that they considered beneficial to their "clients." It became a meaningless "buzzword."

So, where are we now? We began the talk about a recovery oriented system where the focus was not on an illness. Many excellent articles have been written about recovery – many of which are from other countries and written by consumer/survivors. More and more, documents are being written here in Canada and Ontario about recovery from a consumer/survivor perspective. The mainstream mental health system is now, in some cases, also talking about recovery. It is a word that is often misused and misunderstood and is now in danger of becoming yet another buzzword.

The stated goal of service providers, the government and survivors has always been to make the mental health system more responsive to the needs and wants of people living with mental health issues. This was the rationale for moving hospital bed dollars to the community. The beds are gone – hospitals are operating in many cases with large deficits and have eaten up what mental health dollars they had. The services in the community are under-funded and constantly being asked to do more with less. Although grateful for any bone (or money) thrown our way, budget increases have not come even close to keeping up with inflation, let alone the huge increase in need and demand for our services. The bigger organizations get bigger and the smaller ones are encouraged to partner or amalgamate with other organizations. Meanwhile, there are the consumer/survivor organizations. We have always done more for less – it comes from lives lived on limited incomes from Ontario Disability Support Program (ODSP). We know how to stretch a buck! When hospitals or traditional services have organizational crises, these are taken as par for the course; but when a consumer/survivor organization has a crisis, they are often either forced to close or their funding is moved to a traditional service provider. The discrimination against consumer/survivor organizations by not funding them as equal participants in the support of consumer/survivors in the community continues to be appalling.

We are accused of not knowing how to manage our organizations or our budgets. We have been asking for years for the money to access training, organizational development, leadership development but it doesn't come. There are finally some promising projects in the works but they are all relatively new and the outcome is as yet unknown. For the many consumer/survivor organizations that have been very successful, there is no money to research and document these successes and share this knowledge with our peers. Our cries to be included in the development of best practices goes unheard as research dollars pour into hospitals and universities.

Now, we find ourselves moved to a regionally based system – overseen by the 14 different Local Health Integration Networks (LHINs) across the province. We are starting, in some cases, back at square one in terms of educating professionals about our needs and priorities. Some LHINs have made mental health a priority, some have not. Some listen to the voices of consumer/survivors, some don't. Some have us at the table, some don't.

The Ministry of Health and Long-Term Care was proactive in ensuring that each LHIN region received money for a LHIN based regional network of consumer/survivor groups. These are in place and making progress. A new provincial voice has been formed with the creation of a provincial group made up of each of the 14 lead consumer/survivor organizations that received the money for their area. This provincial voice became a reality because we made it happen out of necessity and we used our very limited regional budgets to get together in person four times per year to address the myriad of issues facing us.

Two provincial membership based consumer/survivor organizations now sit at the table with the "big boys" of mental health – the Centre for Addiction and Mental Health, Canadian Mental Health Association and Ontario Federation of Community Mental Health and Addiction Programs, to name a few. This is a big step forward and we hope that other consumer/survivor voices will join and be heard. The Federation is leading a project that will research the needs of consumer/survivor organizations with the aim of building our capacities.

While several consumer/survivor organizations have disappeared, some have grown and developed incredibly successful initiatives based on the stated needs of their communities and memberships. We have consumer/survivor organizations providing mental health services that were previously delivered only by the traditional service providers. These initiatives are much more reflective of the needs of the consumer/survivor and based on peer support principles.

But, what is the reality for people living with mental health issues today?

We continue to live on ODSP rates which are below the poverty line. In 2006, the poverty line cut-off for a single person living in Toronto was $21,202.[2] In 2007, a single person making the maximum on ODSP had an annual income of $11.998.[3] Although recent changes have been made to allow people to keep a little more of what they may earn by working, there are still huge barriers to both living on ODSP and trying to get off it. Housing shortages are a national tragedy. Employment opportunities are slowly increasing, many through consumer/survivor organizations and alternative businesses but at wages so far below the traditional service providers that it should be an embarrassment to the system. Consumer/survivors say they want housing, a job and a social network (a home, a job and a friend). We may be closer to that goal than we were 25 years ago but we still have a long way to go. Our funders and supporters (which should include traditional service providers) need to wake up and take our demands seriously. We've tried pleading. We've provided the data, and we keep on doing what we're doing – more with less. We need to be funded on parity with the rest of the system if we are truly valued as equals.

We have a provincial partnership to strengthen our voice, the Mental Health Commission of Canada that is taking a strong leadership role with regards to the importance of the voices of consumer/survivor and the Minister of Health and Long-Term Care recently announced a 2.5% increase to all mental health budgets for this year. These developments provide hope but it has taken 25 years. Let's just hope it doesn't take another 25 years to gain parity within the system that wouldn't even exist without us as "clients."

[*] Laurie Hall is a person living with mental health issues. She is currently the Executive Director of A-WAY Express.

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1 Ministry of Health, *Putting People First – The Reform of Mental Health Services in Ontario* (1993).
2 Canadian Council on Social Development, using Statistics Canada's Catalogue # 75 F0002MI.
3 See the Income Security Advocacy Centre website at www.incomesecurity.org

CHANGE IS HOPE, HOPE IS RECOVERY, RECOVERY IS LIVING

Dave Gallson[*]

There was a time, not that very long ago, when persons living with mental illness were locked away in very clinical, cold and uninviting places. They were told how to dress, when to eat, how to behave, who to speak to, what treatment they would receive, and what was "best" for them. Many were given menial tasks such as washing the floors, cleaning bathrooms and washing walls.

Society thought it was doing the "right thing" by removing these persons from the mainstream. In this way, society did not have the burden of accommodating persons who did not fit within the mould of what was considered acceptable.

Over a period of time, two very different sets of issues at opposite ends of our social network were created. One was that the persons with mental health issues were stripped of dignity, choice, opportunity, rehabilitative options, compassion and hope. At the other end, persons who were making decisions began to realize the burden of control was often eased through the use of drugs and other less humane treatments – this power which was indeed intoxicating.

The saying, *the more things change the more they stay the same*, has a particularity truthful ring. Who amongst us does not know someone living in a retirement home where tranquility is brought on by the over-prescription of numbing and sleep inducing medication? Why is society not pounding on the front doors demanding change? Surely, this cannot be right!

We are all aging. As we ourselves move towards those days of less resistance and lowered voices, will our cries from within those walls of unacceptable treatment be heard or will those within listening range have more important things to do?

Changes come from those strong individuals that stand up and demand improved methods of conducting services and programs. Persons using services are the most effective filter which separates the good from the bad. Like a peach at the grocers that is turning bad, persons will avoid it until it has completely lost all semblance of being edible; at that point, it is quickly discarded. Governments must accept and indeed *preference* the views and recommendations of the lived experiences of the persons using these services; for these are the real subject experts.

The most significant factor which has facilitated change has been increased communications and the dissemination of information. The public was slowly informed as to what was actually happening in these traditionally secretive buildings tucked away behind immaculately manicured landscapes and trees. Human faces were attached to residents, stories were told and relatives began to speak out and unite. This began to light a new tunnel. Over the next twenty-five years, we will hopefully see many more changes and witness the final closures of buildings with hidden histories of neglect, abuse, and the cruellest component of all, the total lack of hope.

The most important change that has occurred is the shifting of decision-making responsibilities back to those who are directly affected by this condition – persons living with mental illnesses and their families.

No longer will others dictate what is "best" for us again. Never will we permit our choices to be made by strangers. NOTHING ABOUT US WITHOUT US.

Canada has been somewhat slow in changing. We were the only G8 country to not have a national mental health strategy. Our society has now turned the corner. In 2007, the Government of Canada, through the courageous efforts of the Standing Senate Committee on Social Affairs, Science and Technology, chaired by the Honourable Michael J. Kirby, produced a national report on mental health, mental illness and addictions which lead to the establishment of the Mental Health Commission of Canada. This process and new commission has championed, and holds at its core, the rights of persons living with mental health issues in Canada.

Many new programs have been created to provide assistance and supports for persons who are affected with mental health issues. Many politicians see the effects of mental health issues within their own families and now realize that an unwillingness to support the advancement of services for the mental health sector on a continuous basis will not be accepted by voters.

There have also been some positive outcomes in other areas, such as the Ontario Disability Support Program (ODSP), which provides income support to persons with mental health issues who are unable to work. Although there are many further changes which need to be made to ODSP, the following changes in 2006 were implemented and serve as a starting point for change:

- An increase in the one-time start up grant from $253 to $500 in order to assist persons in buying appropriate work clothing and bus fare;
- Providing ongoing health care coverage for those leaving ODSP until health care coverage kicks in from the employer. If no coverage exists from the employer, individuals will remain covered by ODSP;
- Instead of a 75% deduction from ODSP for every dollar earned after the first $160, it was reduced to a 50% deduction; and
- Improvements to the rapid re-instatement rules allowing persons who have to leave employment to return to ODSP supports more quickly.

Advances are slowly continuing to be made across the country. In Alberta, for example, a recently re-elected provincial government has promised they will raise the maximum by $500 working income singles, single parents and couples earn without impacting their Alberta Income for the Severely Handicapped (AISH) payments. This could potentially leave an extra $250 a month in the pockets of AISH recipients. Small steps yes, but each step forward takes us further from the past.

Over the last several years, a vast array of new programming and services has been introduced to provide increased options and opportunities to support persons with disabilities in their quest for full inclusion. Federal to provincial/territorial transfers are leading to increased inter-provincial collaborations where sharing and replicating promising practices is occurring. This knowledge transfer leads to the creation of new delivery models ensuring more persons have more choices to self-determine their road to goals and objectives.

The skills and knowledge of the consumer-survivor community have been firmly established, validated and accepted by governments and other stakeholders. The value of learning from persons who have lived through mental health issues can never be underscored enough and has to be accepted by all involved in our mission. Persons living with mental health issues must be at the centre of all initiatives and participate in all decision-making.

Advances have been made and successes achieved. New partnerships and collaborations have been fostered. New attitudes now exist. We are now moving into a period of time where the changes which will transpire will undoubtedly have a positive affect on all families. The establishment of the Mental Health Commission of Canada, the acceptance of the mental health consumer-survivor community as knowledge experts, and the buy-in and support from all levels of government will come together in a powerful collaboration resulting in the next several years seeing the most important advancements in the history of our community across Canada.

Now, that is something we can all be proud to witness.

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THE CREATION OF THE MENTAL HEALTH ADVOCATE ROLE IN NOVA SCOTIA

Andy Cox[*]

It all started in October of 1994 when I was in first year university and I was diagnosed with clinical depression (later bipolar disorder). As we all know, this is a common age for the first diagnosis of a mental illness.

The next seven years were literally 'up and down.' I was in and out of university for seven years and, at the same time, in and out of hell. I spent a considerable amount of time as a young person in psychiatric hospitals.

Once finally well, I started working in the non-profit mental health world. I helped start and run a Youth Net site in Halifax (Youth Net being a 'youth-for-youth' mental health organization developed by Simon Davidson and Ian Manion at the Children's Hospital of Eastern Ontario). Then I became an employment counsellor for youth with mental illness. In the meantime, I became very involved with mental health advocacy, being a part of various government, hospital, and non-profit boards and committees. I was on an advisory committee for the mental health program in our children's hospital, the IWK Health Centre. Hearing about the experiences from the youth with whom I worked and being connected to the youth mental health system, I realized, as when I was younger, that the mental health systems of this country had a long way to go.

I decided to do some research on mental health advocacy, which included the Psychiatric Patient Advocate Office. I worked on a proposal to create the position of Mental Health Advocate at the IWK. After a couple of submissions, it was approved.

In January of 2004, when I first began the job as Mental Health Advocate for children and youth at the IWK Health Centre in Halifax, there were already controversies because of the unknown nature of the position. First, there was some suspicion as to why I was there. 'Was I there to watch everybody?' 'Was I there to look for problems?' I handled this by concentrating on creating relationships with everybody and letting them know this wasn't about staff versus family, patient, and advocate.

Another issue which came up, still a hot topic with some, is the fact that I was mandated to advocate for the rights of children and youth but employed by the hospital where they were patients. Some say that this is a conflict of interest, setting limitations on what I could do. Should I be employed by an outside agency or non-profit organization? I still wrestle with this. For now, not much can be done about this and I look at the positives of being on the 'inside' – I have been able to help youth in ways I couldn't from the 'outside' (e.g., total access to all patients/families, charts, staff, policy and committees anytime I want). I have also been able to create systemic change within the hospital.

In 2005, I was asked by the then Senator Michael Kirby to go to Ottawa to attend a meeting about child and adolescent mental health with experts across the country. This was in preparation for the report by the Standing Senate Committee on Social Affairs, Science, and Technology that was looking at the gaps in mental health in Canada. Later, I was interviewed as a witness for the actual report, *Out of the Shadows At Last*, which led to the establishment of the Mental Health Commission of Canada

Then, while away on vacation in August of 2007, I checked my voicemail at work and Senator Kirby, now the Chair of the Mental Health Commission of Canada, asked me to give him a call. It ended up that he wanted me to be on the board of the Mental Health Commission of Canada.

The following are remarks I made in introductions at the first board meeting in September of 2007 about my vision of what I wanted to see the Commission do:

- I want a 17 year old to be knowledgeable enough to recognize symptoms of a mental illness if an illness occurs.
- I want that 17 year old to be able to tell his friends and family he has a mental illness and needs help.
- I want his university professors to be educated enough around mental illness, just like the understanding of his fellow blind student who needs adaptive technology.

- I want him to be able to get good mental health help and accurate advice from his GP, and be able to be referred to a psychiatrist to be seen immediately with access to a full treatment team (just as an operation requires surgeons, nurses, and an anaesthesiologist).
- I want the psychiatrist to be able to see him as often as necessary, allow appointments to be as long as necessary, and to listen to him and his family as part of a partnership. I want his family to be treated with respect and heard.
- Their office must exist in the small rural town he lives in.
- I want the treatment team to be able to provide or find a peer support group or program; and one to support his family as well.
- I want a well developed and organized mobile crisis team in the event that he needs it.
- I want the police to understand mental illness, to prevent guilt and embarrassment.
- I want somewhere in which the youth, his family, his friends, his professors, and his clinicians can access the latest on mental illness and how to get help and navigate the systems.
- I want the youth to feel comfortable walking down the streets in his hometown.
- I don't want him to lose friends because of his illness.
- I want him to be able to take his nightly Lithium while his roommate takes his nightly puffers.
- I want his church to accept him and mental illness.
- I don't want him to hear 'pull up your socks'.
- I want him to have the option of psychotherapy and other treatments to go along with the proper medication.
- I want him, along with his treatment team, family, and university to develop and support a plan to get back into university.
- I want the student's university to refund an appropriate amount of tuition, just like his classmate who had to leave because of a car accident.
- I want to see one of his favourite rock stars disclose his/her mental illness and appear on TV commercials and talk shows.
- After finally getting stable, I don't want him to be pitching a baseball game and the opposing coach, a father, yell aloud "the pitcher needs more pills".
- When stable and well I want him to have as much support as possible to try to avoid getting sick again.
- I don't want him to resort to alcohol to temporarily relieve his pain, which makes matters worse in the long run.
- During treatment I don't want pills to be added to pills to be added to more pills – with no other help.
- I want his friends, family, fellow students, and co-workers to be able to recognized him, staying up all night, creating obscure art and projects, speaking fast but not fast enough to keep up with his thoughts, and partying hard may not be innocent fun; but that he may be experiencing mania and needs help.
- I don't want him to be in and out of university, taking seven years to get his degree.
- I don't want the government to cut funding for not-for-profit programs, like the one he used to get back into the workforce.
- I want his employer to understand as if he had cancer, and be flexible in his work.
- I don't want his girlfriend of over 2 years to leave him because he got sick again and she cannot longer deal with it.
- I don't want him to die from this potentially fatal disease.
- And I don't want him to go to his first national Mental Health Commission meeting and have his cab driver wish him good luck at the 'nut meeting'; or have the person greeting him in the elevator look at his name tag and suggest that his day's meeting will probably make him 'mental.'

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SELF-HELP: AN IMPORTANT BUILDING BLOCK IN RECOVERY

Linda Bayers*

Every day in Canada, thousands of individuals are meeting face-to-face or online in self-help groups (SHGs). In terms of mental health and illness, there are groups for persons living with depression, bipolar disorder, obsessive compulsive disorder, anorexia bulimia, obsessive compulsive disorder, anxiety, stress, and schizophrenia, as well as groups for their families and friends. SHGs are based on the tandem concepts of mutual aid and self-help. Mutual aid or mutual help refers to individuals joining together to assist one another, either emotionally, socially or materially. Self-help refers to an individual taking action to help him or herself, often drawing on latent internal resources and healing powers within the context of his or her lived experience with an issue. Joining the two concepts is the saying, "You alone can do it but you can't do it alone."

"You alone can do it" implies self-responsibility and independence whereas "you can't do it alone" implies mutual aid and dependence. Joining these two produces a special form of interdependence in which individuals accept responsibility within a mutual aid context. In other words, individuals maintain independence while helping others, and receiving help from them. The term "self-help" refers to this synergistic interdependence resulting from the combination of self-help and mutual aid where individuals learn to give help, receive help, and help themselves. As self-helpers, say "helping helps me."

What can SHGs provide individuals in recovery from mental illness? Lots. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. Persons in recovery (PIRs) often refer to recovery as a journey, not a destination. It involves learning to live with, through and beyond the symptoms of the illness and all the side effects of the medication and treatments, and having the life that you want and deserve. It is about controlling the illness instead of the illness controlling you. The individual, or person, is at the centre of recovery, and intervention – not their illness.

Recovery from the consequences of an illness is sometimes more difficult than recovering from the illness itself. These consequences may include discrimination, poverty, segregation, stigma and iatrogenic effects of treatment. Core beliefs underpin the concept of recovery whereby PIRs: function well in society with supports; make a positive contribution to society; learn ways to cope with symptoms; use knowledge of mental illness as a source of knowledge; learn from and teach other consumers; and CAN and DO RECOVER.

As an important building block, self-help has the potential to:

- Provide emotional and social support;
- Help members get information on coping, treatment, and treatment options;
- Improve the quality of life, or the impact of illness on the body, mind and spirit;
- Help in the formation of an identity as a capable survivor who is in control of her/his life;
- Instil hope, or a sense that it is possible to rebuild a positive self-image;
- Provide resources for living life to the fullest;
- Act as a role model;
- Provide constructive and supportive ways to facilitate better working relationships with health professionals and negotiate "expert" systems; and
- Help destigmatize the problem by encouraging others to seek the right treatment, at the right place, at the right time.

Emotional and Social Support

Individuals who are experiencing a mental illness often feel isolated, fearful, stressed, stigmatized, discriminated against, angry, and self-blaming. They often believe that they are the only one who feels this way, and don't know where to turn for help. Group members can help members express these feeling, acknowledge them as valid, and provide the support of someone "who has been there" and "knows what you are going through." Group members are important and understanding allies on the healing journey as PIRs move forward in feeling "normal" again.

Obtaining Information

PIRs want to recover. Groups help them find, access, and create those tools. Groups use an amazing number of traditional and creative strategies and tools – discussions, storytelling, study groups, problem solving, role-playing, guest speakers, research, online searches, lived experiences and the collective wisdom of the "teaching voices" of members. Informed patients are better able to face treatment and to understand the uncertainties, challenges, vulnerabilities, insights, and joys involved in recovery. Groups also serve to help members interpret and mediate technical and professional information for other group members. This "kind" of help is not available in a doctor's office. Most importantly, PIRs can learn ways to be responsible for their own recovery.

Improving Quality of Life

Groups can provide ways to alleviate or cope with symptoms, especially the side effects of medication, the reduction of stress and anxiety, the feeling of control, and a deeper spiritual understanding of the "self."

Formation of an Identity

PIRs refuse to play the victim; instead, they create their own culture and organizations. They learn to take greater control of their own health by demanding information, choices, dignity, and the full rights of citizenship. Groups help members get beyond a victim or sufferer stage to form identities as capable persons who can take charge, form social relationships, hold down jobs, and create the future they want. They help put illness in perspective as only one part of the many identities and "hats" we all wear as full participants in the social fabric – as mothers, fathers, spouses, partners, brothers, sisters, co-workers, friends, and so on. The group provides a haven where members can honestly and freely talk about their experiences and concerns without fear of feeling judged or criticized.

Instilling Hope

Group members experience a sense of closeness and strength that emerges in difficult times. They may hope for a better day, a better week, recovery, sometimes "one day at a time." As Margaret Somerville says: "Hope is the oxygen of the human spirit."

Providing Resources

While self-help groups are not therapy groups, they are therapeutic in that they offer several therapeutic factors such as the instillation of hope, catharsis, and altruism. As captured in the well-known group saying, "helping you helps me." First described by Frank Riessman in 1965, the helper-therapy principle is based on the concept that those who help others gain special reciprocal benefits themselves through increased self-esteem, competency, self-worth, and belonging to the "bigger picture." Helpers then develop a firmer understanding of their own recovery process and goals.

Acting as a Role Model

Group members may be at different stages in the recovery journey. Members are not just saying, "I did it, you can too." They are showing that success and recovery is possible. For those who are still having a hard time, the group acts as a cheerleader, providing encouragement and hope that change and a better day are possible. The episodic nature of severe mental illness does not prevent recovery. As one recovers, symptoms interfere with functioning less often and for briefer periods of time. More of one's life is lived symptom-free. The process of struggle can result in an individual's taking responsibility for their behaviour and becoming empowered or not. The group provides many shared assets, created by, with and for all members. The more you put in, the more you take out.

Facilitating Better Working Relationships with Health Professionals

SHGs share ways that have proved successful in communicating with doctors. Simple tips such as "write down the questions you want to ask the doctor" can help PIRs speak up about their concerns. Many groups also collaborate with professionals. For example, a group may ask a local health professional to speak to the group on new treatments, or participate as a respondent in a university research study, or pass out literature from the local mental health clinic at a group meeting. In turn, professionals may refer individuals to local groups, or pass out the group's brochure to potential members, or invite a group member to speak at an in-service, staff meeting, or conference. Groups indicate they prefer professionals to play roles as providers of referrals, advisors, mentors, and consultants. Groups provide respectful and professional ways to get their needs met when dealing with health care, legal, or social service systems in terms of accessing services. Members learn ways to take personal and collective action on health issues.

Destigmatization by Encouragement

While SHGs can provide many resources for recovery, groups are not for everyone. For those who are interested in finding out more about groups in your area, or starting your own group, please visit the Self-Help Connection website at www.selfhelpconnection.ca. We recommend checking out a group by talking to the group's contact person, attending a group meeting, and deciding for yourself whether or not the group is a good fit. Also, check out the website of the American Self-Help Clearinghouse at www.selfhelpgroups.org or http://mentalhelp.net/selfhelp/ for a list of American, Canadian and International Self-Help Resource Centres, and more than 1100 model groups.

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ELECTRO-CONVULSIVE THERAPY: ETHICAL CONSIDERATIONS

Annie Jollymore[*]

"[ECT] offers a very poor trade-off—potentially irreversible brain damage and mental dysfunction in exchange for the docility and temporary emotional blunting or euphoria that result from the damage."[1]

--Peter R. Breggin, M.D.

As a Systemic Advocate with a consumer/survivor organization, I hear pleas from family members to advocate for mandatory treatment for their sons and daughters with schizophrenia, bipolar disorder or severe clinical depression; they say these young people are too ill to possess insight into their illness. *Youth with brain diseases cannot hope for recovery until the underlying pathology is treated*, desperate parents plead.

I also hear horrific stories from psychiatric survivors about coerced treatment, injuries inflicted from the use of restraints and drugging and torture with "electroshock" therapy.

It is hard to find a middle ground between these groups who often perceive the same psychiatric intervention from totally opposite perspectives. Yet it is essential to try. It is heartbreaking to see individuals exhibiting untreated – or inadequately treated – psychoses spiral downward into poverty and homelessness, often winding up in the criminal justice system. It is also saddening to see the desperation and anger on the faces of the people who love them when assessment and treatments are inaccessible or rejected.

What is ECT?

Electro-convulsive therapy (ECT), also called electroshock, is a psychiatric treatment in which a grand mal seizure is induced by passing electricity through the brain of an anaesthetized patient. It is generally used to treat severe depression in patients who do not respond optimally to medications or psychotherapy.

Introduced in 1938 by Italian physician Dr. Ugo Cerletti, who was intrigued by the effect of electricity administered to the brains of pigs destined for slaughter, ECT is the most controversial treatment in psychiatry. The shocks rendered the animals unconscious but did not kill them. In fact, the animals could survive the shock if allowed to recover.[2]

Cerletti also found that electroshock rendered his "obsessive and difficult" mentally ill patients meek and manageable. Insulin shock therapy, in which large quantities of insulin are administered to chemically induce a coma lasting about an hour, was also being used on mentally disordered patients. Other doctors quickly adopted these new treatments which were cheap, easy to administer, and made "unmanageable" persons manageable.

Its history of abuse, sensationalized media portrayal and testimony of former patients all contributed to the divisive context in which ECT was – and still is – viewed. The social pressure to ban this treatment, which is viewed by many as torture, and the introduction of neuroleptic drugs in the 1950s and 1960s, reduced the frequency with which ECT was utilized.

However, ECT is now on the rise in North America. Insurance companies approve it as a faster, more economical "medical" treatment than psychotherapy. The people for whom it is prescribed today are largely vulnerable elderly women. But it is also being used on pregnant women and persons with developmental disorders. From 2001 to 2002, over 14,000 ECT treatments took place in Ontario. The majority of these treatments were administered to female patients in "locked units" – one third of who were aged 65 or older.[3]

Don Weitz, insulin-shock survivor and co-founder of the Coalition Against Psychiatric Assault (CAPA) calls ECT a 'human rights violation and psychiatric atrocity'[4] that has no place in a society that sees itself as civilized, humane or compassionate.

Medical Perspective

Many psychiatrists disagree with the view of patients' rights groups about ECT. In *Electroshock: Restoring the Mind*, Max Fink, M.D. asserts that:

> ECT has undergone fundamental changes since its introduction 65 years ago. It is no longer the bone-breaking, memory-modifying, fearsome treatment pictured in films. Anaesthesia, controlled oxygenation, and muscle relaxation make the procedure so safe that the risks are less than those which accompany the use of several psycho-tropic drugs. Indeed, for the elderly, the systemically ill, and pregnant women, electroshock is a safer treatment for mental illness than any alternative.[5]

Therapy or Crime?

The question of whether ECT is a safe and effective therapy or a medically sanctioned crime should be moot. When it is determined that a treatment has adverse effects, such that injury or death could be a result of its use, medical ethics dictate that it be withdrawn. In this country, consumers have a right to expect that physicians are informed about the medications they prescribe, that drug manufacturers thoroughly test their products, and that government agencies strictly regulate which drugs receive approval.

It is hardly a stretch to ask why ECT has not been abolished. If even a small number of individuals have been harmed by ECT, the risk to those few outweighs the possible benefit to others.

Informed Consent

According to some patients' rights groups, there is no such thing as "informed consent" to ECT. There is widespread belief that psychiatrists routinely *refuse* to inform patients about the serious risks of permanent memory loss and brain damage that result from ECT and hospitals and other facilities where ECT is administered are inherently coercive.

The ethical and legal issues regarding the use of ECT encompass the decision-making process in the doctor-patient relationship, the principle of the right to refuse treatment, and the social dynamic relating to historical and contemporary use of ECT.

Psychiatrists are charged with ensuring that their patients receive care appropriate to their condition. In-patient psychiatric treatment may seem at times an almost adversarial process, pitting psychiatrist against patient, or patient against psychiatrist, family, community agencies and the police. Patients often exhibit fluctuating capacity during a hospital stay, and capacity to consent to treatment may vary depending on the treatment being proposed and the potential harm associated with it.[6]

Individuals with mental disorders are a vulnerable and sometimes defiant group; treatment goals may be difficult to define and recovery tends to be non-linear and slow. Clients may present with frustrating self-neglect or risk-taking behaviours due to non-compliance with treatment. A patient's emotional experience of illness may conflict with the doctor's own attitudes and beliefs, and patients may be regarded as manipulative when they are in fact exhibiting vacillating reactions to their illness and its psycho-social consequences. A patient's emotions may fluctuate between vulnerability and dependence at one moment and dismissal and denial of mental health problems at another.

While mental capacity may fluctuate with degree of illness, this variability may also reflect a reaction to fundamental changes to an individual's liberty or right to make choices. Few mental health clients are provided with a full and fair opportunity to have their voices heard when it matters the most.

Treatment non-compliance has been widely researched. It has been estimated that up to 60% of patients suffering from depression do not comply with drug-treatment programs.[7] But consent to ECT is a different matter; a patient may refuse treatment, but she has no control over its administration.

In theory, treatment plans must be developed by the patient and the doctor jointly; in practice, this may not happen. Most doctors discuss proposed treatments with their patients, but not all doctors offer their patients a choice. The patient may perceive undue pressure –such as economic pressure in the form of non-payment of disability benefits – to accept a course of treatment that includes ECT.

Informed consent is the key to protecting a patient's autonomy. But depression, or other mental distress, may itself impair a person's ability to make an informed decision about ECT. Consent at the outset of treatment must not be the final dialogue on the issue. Due to temporary or permanent memory loss and confusion following ECT, a patient who has given her consent to the treatment may not remember doing so at a subsequent treatment session. She may therefore perceive the treatment as coercive and imposed against her will. Periodic reviews must be initiated by the psychiatrist and not depend on the patient – or in the case of an individual who is deemed incapable of making her own treatment decisions – a substitute decision maker to withdraw consent.

As Susan Friday notes in Informed Consent and Mental Health Legislation:

> Anyone who through any element of force accepts a medical treatment or drug has had their rights violated under the Canadian *Charter of Rights and Freedoms*. Their rights to life, liberty and security of the person have been violated, as well as their rights to equal protection and their rights not to be the subject of cruel and unusual treatment or punishment for refusing or attempting to refuse an unwanted drug or medical treatment...[8]

Neither the efficacy nor the safety of ECT has been proven through independent scientific research. Psychiatrists and other physicians continue to administer ECT to vulnerable patients, while opponents maintain that ECT robs people "of their memories, their emotions and their creativity leaving behind a docile, complacent, zombie-like shell of a human being."[9] As long as ECT is used to treat mental disorders, patients must be fully informed about the nature and purpose of the treatment; expected treatment outcomes; temporary side effects and the risk of permanent brain damage; and alternative treatment options and their foreseeable risks and benefits.

Clear communication may help mitigate perceptions of coercion.

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ART, HEALING AND MENTAL HEALTH

Anne Sloboda [*†]

The making of art and working with art and craft media has been a part of many institutions for the care of the mentally ill since the mid 1800s and the beginning of the modern "asylums." For many years, the inmates of these asylums were allowed and even encouraged to create their art without much direct intervention or direction from physicians or therapists. The resulting work, however, was well documented and it intrigued and fascinated both artists and scientists who saw it. The general public began to become aware of this art with the publication of books such as "Art of the Mad" by Marcel Reja, published in 1907.[1]

Art therapy began to emerge in the 1930s and 1940s as a means of using the process of making art to help people with mental illness deal with their condition and explore their inner world. However, many people come to art on their own, having discovered by themselves that making art helped them cope and made them feel more alive, giving them a sense of accomplishment and mastery.

Art-making seems to be an intrinsically helpful and healing process for most people. What do we do when children are bored or upset? We give them crayons and paper and let them colour. What do we do in a long or stressful meeting? We doodle on our notes. What do we do to relax in our own homes? Many of us build things, draw plans for imaginary houses or gardens, fuss over colours for quilts or rooms. We create, regardless of medium, because creating makes us feel good.

The process of creating and sharing one's art is an extremely effective method of dealing with all kinds of problems, but particularly problems involving mental illness because of the many ways that art-making affects the body, mind and spirit. First, the involvement that creating art evokes allows the mind to enter into a state called flow by Mihaly Csikszentmihalyi.[2] Flow is a state where sense of time disappears, awareness of self is reduced and brain wave activity is similar to that of deep meditation. Being in the state of flow literally takes one away from one's self and current problems. It gives the body a break from stress and the resulting physiological reactions of stress. Art-making gives people a place to go to for rest and regeneration.

Secondly, that same state of flow focuses the mind on the work at hand. The "inner chatter" of the mind is over ridden by involvement in the process of making art. Thought, as such, is reduced to concentrating on holding the brush, shaping the line, choosing the colour. In art therapy group sessions, most groups will generally become increasingly silent as people become more involved in the artwork until an intense quiet takes over the whole room. The time spent making art is time spent not thinking about one's illness, one's situation or one's self. It is time spent in which the world is a sheet of paper or a lump of clay and all that matters is the process of shaping that world.

Thirdly, the spirit is engaged because the work of creating something allies one with the creative spirit itself. Whether you choose to think that an artist is connecting with a muse, the collective unconscious or the creator spirit is not important. What is important is the sense that it is not the "self" inspiring the art. Artists will often speak of ideas or images coming from "outside" themselves, or of a feeling of tapping into some greater energy that feeds their work. Many artists, particularly those who deal with emotional and mental illness, will ask for assistance and guidance in creating their work. Drawing on a transpersonal source of strength and support gives healing benefits to the person as well as imbuing the piece they are creating with some of that sacred spirit.

Sharing one's artwork is a way of inviting someone else into our world, and showing them how we feel about that world, and how we perceive it. Art, particularly visual art and music, communicates in a very direct and visceral way. Something that is hard to put into words can sometimes be put into pictures far more easily. Experiences, like personal trauma and/or pain that cannot be communicated directly because they are too raw or too personal, can be presented symbolically through images and colour. Feelings can be expressed and shared with others while still giving the artist the protective distance of being separate from the work. An artist can sometimes talk about the content of a work when they cannot talk about the experience that led to the creation of that work.

The power of art is to communicate with others and transform the world of the viewer by giving them a glimpse into a different place. The place that people with mental and emotional disorders come can be a vivid and disturbing place, so the art they make is often vivid and disturbing, but also exhilarating and uplifting. The art world in general has long had a fascination with "Outsider Art" or "Art Brut" because of the strength and the originality of images created by those living and working outside the standard art gallery or art school system.

Outsider Art, unfortunately though, is not a label like "Group of Seven" or "Dada" that designates a particular style or affiliation or political stance that is voluntarily adopted by a group of like minded individuals. "Outsider Art" defines the artists in terms of their relationship to the greater community. Outsider Art, like the outsiders who create it, does not fit into our everyday predictable world. The decision to create the "Healing Palette" as an art exhibition and an organization to promote understanding of mental illness through art was partly an impulse to bring together the two worlds. It was also the desire to share the idea that mental illness can be a gift, albeit a "perilous" gift, rather than purely an affliction or burden.

The concept of the exhibition came from Deb Underwood, an artist with first hand experience of the effects of mental illness upon one's life. The making of her art was a major part of her survival and healing, helping her to understand and live with her illness in a very positive way.

As part of her journey, Deb became deeply involved with the spiritual uses of labyrinths and labyrinth walking. Deb successfully organized the creation of a full size walking labyrinth in Waterworks Park in St. Thomas that was installed with the cooperation of the parks department. One of the walks Deb took in the labyrinth was a search for a means of bringing to the larger community a sense of what art can mean to survivors. She knew that art was one tool that could really express the journey taken and share the experience of mental illness with all its highs and lows. The answer that came to her was a public art show of works by survivors.

When Deb connected with Reverend Stephen Yeo, chaplain at Regional Mental Health Care, St. Thomas, he immediately supported her vision and offered to pull together a group of colleagues to help bring the vision into reality. That group organized the first Healing Palette exhibition in October of 2006 and is helping to shape the exhibition into an annual event that encompasses written, spoken and musical work as well as visual and sculptural work. Right from the beginning, the show has been a great success. The Elgin St. Thomas Art Centre originally agreed to host the show for a four day period and ended up extending the show to a full month run. It is the hope of the group to continue to use the exhibition as a means to reach out and build powerful connections between the inner world of mental illness and the outer world of the general community.

The Healing Palette is part of a grassroots movement that encompasses self-run open studios for survivors such as the City Art Centre in London, Ontario, and Artbeat Studio, founded by Nigel Bart in Winnipeg, Manitoba. Other art shows such as the Touched by Fire show at the Gladstone Hotel in Toronto, Framing the Phoenix art show at the London Arts Project, in London, Ontario have sprung up to share the work and the experiences of artist/survivors.

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[†] I am writing this article on behalf of the Friends of the Healing Palette.

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PEER SUPPORT/TRAINING: PITCHING FOR A 'BEST PRACTICE' IN ONTARIO

Brian McKinnon*

The consumer/survivor initiatives (CSIs) of Ontario are known for their good work in the areas of peer support, community development, education, recreation, employment and other services. Since their inception in the early 1990s, they have enabled personal growth, recovery and empowerment among their members. CSIs have also made a unique and significant contribution to the work culture of community mental health in both their individual areas and throughout Ontario. They have demonstrated effectiveness, innovation, and leadership even while under-funded.

Notwithstanding their excellent work, the consumer/survivor initiatives do not receive the credit they deserve. Even worse is the fact that CSIs have not seen a significant funding increase since their inception. This is perhaps one of the reasons why the actual numbers of CSIs have decreased while others have been absorbed by mainstream mental health services. Although various mental health reform documents have recommended increased support for the consumer/survivor sector, and the Ministry of Health and Long-Term Care and local health integrated networks (LHINs) usually avow support for the consumer/survivor sector, very little happens.

It is thus important and necessary to advocate that more be done for the CSIs and the consumer/survivor community of Ontario. Any number of possibilities could be number one on the priority list, but for the purposes of this brief paper, it calls for dedicated funding for peer support training for all CSIs. Consumer/survivor initiatives are not limited to peer support but it is central to their work, as well as that of the survivor movement.

Peer Support Works

Peer support offers a unique benefit to people experiencing mental distress; it helps them with their distress at the same time as it mirrors their strengths and potential. With a peer who has walked in their shoes they can see a new path, and it helps them recast themselves in roles other than 'victim,' 'patient' and 'disabled.' Shute, Storey and Thompson quote others in the field before constructing a trajectory from peer support to hope:

> 'Recovery from mental illness lies in undoing the cultural process of developing careers as mental patients. We do this by practicing relationships in a different way.' (Mead, Hilton & Curtis) Peer support, therefore, becomes a natural extension and expansion of community rather than modeling professional caretaking of people defined as defective. As peers feel less stuck in their roles as 'patients,' they naturally come to understand their problems in the larger social and political context from which they emerge, rather than pathologizing themselves. Peer support is a simultaneous movement towards autonomy and community building. It is not based in deficits model thinking. It is a model that encourages diversity rather than homogeneity, and recognizes individual strengths rather than focusing on weaknesses.[1]

Lives are transformed by connecting with peers who have been to dark places, found their way home to wellness, and who know how to support someone on a difficult journey. Davidson reflects on the importance of the work of peer support workers:

> Early in treatment, peer providers may possess distinctive skills in communicating positive regard, understanding, and acceptance to clients and a facility for increasing participation among the most disengaged...Findings strongly suggest that peer providers serve a valued role in quickly forging therapeutic connections with persons typically considered to be among the most alienated from the health care service system.[2]

Some of the positive outcomes of peer support include "decreased hospitalization, increased community tenure, improved quality of life, fewer reported life problems and improved social functioning."[3] For peer support workers, their employment has led to "personal and professional growth, increased financial resources, and increased self-satisfaction." These outcomes have not gone entirely unnoticed. In some jurisdictions, peer support in mental health has been described as an "emerging best practice."[4]

Funding a 'Best Practice'

Outside Ontario, the recovery movement has provided the spark for impressive changes in mental health reform. The work has progressed to a level where peer support has been implemented state-wide and peer support services are getting comparable recovery outcomes as that of case management services.[5] In thirteen American states, peer support and peer support training are funded by Medicaid as it has increased community stability and decreased in-patient recidivism.

Positive outcomes did not occur without leadership from the survivor community. Initially it was the National

Empowerment Center based in Massachusetts that pushed for the development of 'technical assistance centers' which provided training in the areas of peer support and advocacy. In Georgia, the Georgia Mental Health Consumers developed a peer support training curriculum, shared it with their community, and its success led to peer support being mandated in all of the state's community mental health settings. And, it was the success of the Georgia model and the backing of Medicaid that persuaded the federal authorities to fund peer support training in the aforementioned thirteen states. Other state mental health authorities have invested heavily in WRAP (Wellness Recovery Action Plan) training. And, many survivors are being funded to receive training in "trauma-informed intentional peer support" as per the work of Shery Mead.

Peer support training is important for the services provided by CSIs, and people who are entrusted to work as peer workers need opportunities for skill development and access to those with the expertise and willingness to share their knowledge. Some CSIs have responded to this need and taken the lead in peer support training by developing training curriculum, training numerous people, documenting their successes, refining their model and sharing their knowledge with other agencies.

There are several examples of successful Ontario CSIs that are leading the way in peer support training. The Mental Health Rights Coalition in Hamilton is a long-time leader in peer support training and has made an indelible impression in the wider Hamilton community mental health system. The Mental Health Support Network in Belleville links four other sister agencies in the Hastings Prince Edward County, and has integrated peer support training as the glue that makes the Network strong. The Self Help Alliance similarly links three sister agencies in Guelph, Cambridge and Kitchener, and they have made a unique contribution to peer support/training via their focus on recovery values, system reform, leadership and recovery education for mental health professionals. Like Minds, a regional group in Central East Ontario utilizes "Pathways to Recovery" and WRAP in their peer education programs, and place great emphasis on wellness, leadership, anti-discrimination and advocacy. Like Minds has trained numerous people in the region who are networking, and keen to learn more and apply their new-found expertise.

Looking for Hope

Allies are key to advancing the cause for peer support training. However, we are advocating for peer support education at a time when it seems that the CSIs are rather isolated and fighting an uphill battle. In one notable exception, CSIs received a solid endorsement for their work from the Ontario Federation of Community Mental Health and Addictions. The Federation collaborated with the Ontario Peer Development Initiative to produce a lobby paper that documented the considerable achievements of CSIs, as well as the significant challenges impeding their progress, and recommended that the Ministry "double CSI funding."[6]

As there have been some positive developments recently, we remain hopeful that the peer support sector will eventually receive its due recognition. The Ministry of Health and Long-Term Care has established the "consumer/survivor builder initiative" to consult with consumer/survivor agencies and to document recommendations of how the Ministry and the LHINs could strengthen and enhance the peer support sector. In so doing, the Ministry has opened the door to hope; on the other hand, it has also raised skepticism that the process will lead to substantive change.

Another positive sign is the creation of the Mental Health Commission of Canada which is supportive of consumer/survivor empowerment generally, and peer support specifically. The Commission states: "The rise of the self-help movement in mental health and addictions heralds a significant change in our systems of care. With sufficient and regular funding, combined with the ongoing commitment and protection of government, its full benefits will be realized." More specifically, the Commission recommended "a network of self-help and peer support initiatives throughout the country." Among other helpful suggestions, the Commission suggests "that broad-based coalitions be funded and built among self-help and peer support organizations so that they do not continue to exist in isolation but are able to form networks with each other."[7]

Conclusion

It would be extraordinary if the Mental Health Commission's work resulted in significant reform and substantial support for the consumer/survivor sector in Ontario and across Canada. Given the slow pace of change in mental health reform however one should not be overly optimistic. In order for these proposed reforms to be successfully implemented, there has to be sustained leadership and dialogue on the part of politicians, health policy-makers, mental health providers and survivors. This is not likely to happen unless consumer/survivor leadership is able to assert itself in respect of its important contribution to peer recovery. The value of peer support and training has to be stressed in the mental health funding debates at the same time that CSIs emphasize their distinctive role, efficacy and autonomy.

The rest of us have to assist them in this campaign – but will we do so? Mental health professionals have signaled their interest in peer support and training and most people are moved by the recovery narrative. They do understand that people's recovery is tied to peer support. So, why do so few in community mental health take the next step and advocate for that which is proven to work? Is this due to cultural complacency, benign neglect or systemic discrimination? Let's talk about it, and you be the judge.

*Brian McKinnon is a community development worker at Alternatives. His interest in peer support and training stems from his involvement with the Ontario Recovers Campaign.

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THE LANGUAGE OF RECOVERY IN ONTARIO

Jennifer Poole*

Introduction

Born of American survivors,[1] personal stories and Maori teachings,[2] recovery has become a fixture in mental health circles worldwide. Known as the recovery vision,[3] mental health recovery or the recovery movement,[4] in some areas it has become as commonplace as empowerment and so established that it was adopted by President Bush's New Freedom Commission on Mental Health. Thanks to Harding, Deegan, Anthony, Meade, Jacobson, Baker and Thompson, we have come to know what recovery is, how to apply it and what it might mean for promoting and achieving true mental health.

Yet, apart from Robert MacKay's work,[5] comparatively little interest has been displayed in what I call local 'recovery talk' or the language of recovery here in Ontario. Most have turned their attention to measuring, modeling, proving and teaching it, but few have explored the words, phrases and devices that have actually given recovery its fuel. Attempting to fill in that gap, I will share some of the results of a larger research study that asked why are we talking about recovery here, how to we do it and what does it mean for mental health?

The Larger Project

The larger project is an exploration of discourse, one of the notions explored by French philosopher Michel Foucault. Although Foucault had many things to say about discourse, I understand it to mean a collection of sorts, or ways of speaking, writing and acting that cluster around certain new ideas. Most of the time we are unaware of these discourses, but Foucault urged us to dig a little further and practice what he called 'archaeology.' This digging would reveal how discourses come and go, how some become powerful, some recede into history and how each will have certain 'attachments' and rules that tell us how to act, dress or speak. So if we dig into medical discourse, for example, we find words such as 'bipolar' and 'chart,' we find practices such as writing prescriptions and rules around the wearing of 'white coats.'

The study of discourse has been taken up by a variety of scholars, many of whom have argued that how we talk or write about an idea *matters*. If there is real excitement, if *everybody* is talking about *it*, it is more likely to catch the attention of those powerful enough to make change, sway opinion, incite action or even decide funding. Because these outcomes matter, the study of discourse has become central to the field of health research.

With a nod to this work, the larger project asked, what are the prevailing discourses on recovery in Ontario? Who is speaking and/or writing about recovery? What are the words and phrases being used? What are the rules for speaking this language 'properly' and what are the effects of this talk on policy and practice?

How it All Began

I did not mean to study discourse, nor was I particularly interested in reading Foucault. As a community worker long involved in consumer-led mutual aid initiatives, I was more interested in workshops than words and funding rather than phrases. Yet, almost six years ago, I found myself at one of the first recovery 'events' in Toronto. Sitting at Ryerson's Oakham house, I heard research statistics, stories of survival and expert analyses. Looking around that room, I was struck by how each person was speaking about this new 'thing' called recovery. Different were their locations and points of view. Different too were their words and questions. Wanting to know more, I embarked upon my own expedition, delving into discourse and whether these new recovery words (and promises) really signalled hope for change.

Thinking about Language and Mental Health

That journey led me to the University of Toronto and a small group of critical scholars unafraid to ignore the lure of clinical trials and invest their time and hope in qualitative health research. It also led me to my peers in the community, the people I looked to for mental health leadership and those I trusted with the knowledge of my personal recovery work. I asked, "Have you heard of this new recovery 'stuff,' what do you make of it and would it be worth investigating further?" The answer was a resounding yes.

So I crafted a critical discourse analysis, knitting together critical public health thinking, community social work practice, disability writing and Foucault to find out about the language of recovery in Ontario. Being a qualitative research project, it meant I interviewed a smaller number of 'key' people but read a long list of recovery 'texts' such as working papers, internet postings, workshop materials, research, books, articles and recovery reports. It also meant I spent a year analyzing this 'snapshot' of talk and text, looking for themes, questions, differences, surprises and gaps.

What People Said

The results were fascinating. On the topic of recovery language, I found words such as 'growth,' 'cope,' 'empowerment,' 'self-determination,' 'responsibility,' 'spirituality,' 'individual,' 'active' and 'hope.' I found catchy phrases and slogans such as 'recovery in action' and 'from discovery to recovery' as well as similes and metaphors. Indeed, almost all the people I interviewed, including consumers, survivors, family members, educators, policy makers, administrators and professionals, would invoke comparisons when talking about recovery, most commonly likening recovery to the civil rights movement, the feminist movement, the anti-psychiatry movement and the empowerment campaign of the 1980s and 1990s. They also made less than desirable comparisons to marketing campaigns by 'Big Pharma,' historical practices of cost-containment in mental health spending and recent ways in which the (medical) 'empire was striking back' against a social determinants approach. Most common was the metaphor of the journey, linking recovery talk to powerful Judeo-Christian fables, the American dream of individual success and, of course, addictions and self-help discourses.

And why was metaphor so central to the language of recovery in Ontario? One participant suggested we use it because despite recovery's popularity, recovery is still 'airy fairy,' a notion rooted more in emotion, narrative and language than science and measurement.[6] Additionally, my results suggest that there are not one, but five recovery languages in Ontario. Speaking to why, one participant argued, "I think there are very different discourses by how the speaker is situated in the system, whether they are in services, whether they're a provider, whether they're a management or a frontline worker, or maybe a family member" and survivor.[7] I have named these discourses 'story talk,' 'hope and faith talk,' 'professional talk,' 'training talk' and 'marketing talk.'

'Story talk' is always personal, full of self-disclosure and will follow established norms about illness narratives. It will start dark and end with hope, just as Deegan models in 'recovery as a journey of the heart.'[8] 'Hope and faith talk' can be personal too, but its most important hallmark will be references to spirituality, personal epiphanies, 'seeing the light' and finding God. It will be powerful and sometimes evangelical. 'Professional talk' is something different altogether. Full of talk of measurement, evaluation and outcomes, it is about clarifying recovery so it can be channelled into something that can be tracked and tested. 'Training talk' is spoken by those who want to educate and it utilizes recovery tools and models. Finally, there is 'marketing talk,' full of references to selling recovery, creating a 'buzz' and keeping it 'hot.' The most curious thing about all these discourses is that they are being spoken at the same time here in Ontario, making recovery sound good to some, unpalatable to others and according to my research, creating a good deal of confusion and dissent.

Troubling Talk

I address this dissent more fully elsewhere, but briefly I will say it seems to be tied to certain rules around how recovery 'should' be talked about and rules enforced by certain 'players' for certain ends. Speaking to these rules, one participant argued that critiquing recovery is not allowed, nor is questioning its 'royalty,' such as Sherry Meade and Pat Deegan. Another suggested that when talking and writing about recovery, the 'rules' say it has to be positive and hopeful or 'no one is going to listen.' More troubling than the rules however, were those comments from participants who felt that the language of recovery in Ontario had been co-opted and stolen from consumers, survivors and refusers by consultants, workshop leaders and professionals intent on 'hitching their wagons' to something progressive, powerful and potentially lucrative. One survivor argued, "Our language has been taken over by the professional world around recovery, around self-determination, around all this kind of stuff…But it's OUR language!" Although Robert MacKay argues that the language of recovery is a "vibrant, new and living language, being spoken by dynamic, hopeful people"[9] working for consumer and survivors and their allies, it would appear that privately, many of the participants I spoke to seemed to disagree.

Where Do We Go From Here?

Early on in my own research, I read that "one cannot address any part of recovery without soon encountering a larger connected body of ideas, the end of which appears almost limitless."[10] Indeed, I found that participants had a limitless number of things to say about the language of recovery in Ontario. But they were silent as well, not saying too much about whether recovery is really improving mental health policy in Ontario, whether it can really help with housing and poverty and not saying too much about rights. It may be that they are talking to others in the community. It may be that they are keeping their thoughts private, but these issues in particular deserve a good deal more attention from recovery educators, advocates and researchers like me. If we are to see real hope, real wellness and what one participant called 'real recovery,' we have to keep tabs on who is doing the talking in mental health, what they are saying and most importantly, who is listening.

*Jennifer Poole completed her PhD on recovery in 2007 and teaches social work at Ryerson University.

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EMPOWERMENT AND RECOVERY - ARE THEY CONNECTED?

Jennifer Chambers*

Yes. Both are encouraging ideas, aren't they? The powerless get some power, people who struggling are OK – who could object?

Yet these concepts, properly defined, require change. So they inspire, but they also meet with resistance. Theoretically, "empowerment" and "recovery" have been widely accepted as principles to guide mental health services. Now, the question of whether they move us forward or maintain the status quo has come down to how they are defined, and therefore implemented.

I once heard a hospital administrator state to psychiatric consumers and survivors seeking to have some power that "we all have personal power." Potentially true, yet if a person believes that she or he is powerful, but is in fact unable to have any effect on anything, she or he is delusional, are they not?

Empowerment has been defined as everything from a mere feeling to the abolition of the existing power structure in mental health. Perhaps we can agree that empowerment must involve the ability to actually effect change. That power involves decision-making, and the ability to implement those decisions. Ultimately, empowerment means changing power relations between people. The disempowered must have more power, which means the powerful must have less. (Of course if the powerful decide to share, they lose less decision-making ability). Applying this definition to the current psychiatric system, it is apparent that while progress has been made within some mental health services, power is still largely withheld from consumers and survivors, as individuals and as a group.

Recovery means regaining what was lost. For people who have been in the mental patient role, this can be freedom, dignity, peace of mind, work, the ability to think more clearly, self-respect or a personal life. Some people have achieved these things after being told that there was no hope that they could do so. In fact, recovery strictly defined is a limited concept. It is limited to recovering what was there. It does not encompass the experience of people who have emerged as new and better people following their journey into madness and despair. Nor does it recognize the damaging life experience that stopped some people from ever having been OK before they managed somehow to emerge anew. But the idea of recovery is a step closer to a real understanding of people, an improvement over the pronouncement that "you will be seriously mentally ill for the rest of your life, the best you can hope for is symptom management." (By the way, if your service's philosophy is "we have a recovery orientation for people who are chronically mentally ill," you have failed to grasp the meaning.)

These concepts have come to prominence because they have been championed by the psychiatric consumer and survivor movement (and its allies) in order to counteract the powerlessness, hopelessness and learned helplessness the mental health system has often generated. Using personal experience and reference to well conducted research, consumers and survivors have demonstrated that people fare better if they have control over their own lives, and that being told that you are, for example, "schizophrenic" does not in fact mean that you are fated to be mentally disturbed and in need of medication for the rest of your life.[1]

It is important to recognize that while the individual is the one who must be in charge of their own recovery and empowerment, most of the forces preventing it do not originate from within that person (although some may become internalized). It is these impediments that must change for empowerment and recovery to have any meaningful existence in the mental health system.

What has to change and why?

First, let's define our terms. "Empowerment" is the acquisition of power by people without it. "Recovery" I define as the reinvention of your life with you in charge, whatever that might mean for you personally. Both are inextricably intertwined. A social environment that strips a person of any power suppresses the person's ability to be real, while being truly in charge of oneself (a particular challenge for people who have been classified as "mental patients"), can have a ripple effect that can change the world. Gandhi recognized the connection between individual and social change when he said: "You must be the change you would see in the world."

What has to change in the mental health system?

On the individual level, people need to have their self identified needs met.

The results of two studies over eight years funded by the National Institute of Mental Health in the U.S. found that: "Consumers perceptions that their needs were met are the best predictors of positive mental health outcomes."[2] "Consumers' perceptions of their level of service empowerment (e.g. their involvement in treatment planning and decisions about services) was the variable most highly correlated with the degree to which they felt their needs were being met."[3]

Within the mental health system, "consumers do not perceive themselves to be as empowered as they would like to be, with regard to their services and treatment."[4] Some people feel they have had help getting their needs met in the mental health system, some do not. A considerable problem is people being told what they need or directed to one end, rather than assisted in reaching their own informed decision. The all too commonplace violation of the legal requirements for informed consent is an example of this. Rarely are people told what the law requires – the potential risks and alternatives as well as potential benefits to the proposed treatment (which is typically medication). Telling people that they may have no other assistance if they do not comply with medication is another frequent practice. Both of these attempts to manipulate or coerce people are not just ethically problematic (though that should be sufficient cause for concern), they are also ineffective, as the previous study indicates.

A major impediment to the shifting of this attitude is the over-reliance of the mental health system on the medical model, which lets the definition of the problem and the solution reside in an "expert." The attempt to correct this imbalance of power has motivated consumers and survivors to draw attention to the research indicating that much of what has been accepted as scientific fact in the mental health system is in fact, not: psychiatric diagnoses are vulnerable in the areas of reliability and external validity; many features of "schizophrenia" are inconsistent with a brain disease; and recovery is possible regardless of diagnosis and does not necessarily require medication.[5]

Please note that correcting an over-reliance on the medical model in order to better reflect reality is suggesting that it's role be minimized, not that it be abandoned entirely, although people often hear it as such.

Disempowering people through excessive restrictions is also counterproductive to people's wellbeing. One example is a study by Harris and Rice of people in the forensic system: "for offenders at lowest risk, evidence suggests that supervision, detention, and treatment actually increase the risk of violence."[6]

On the systemic level, most mental health facilities in Ontario are underdeveloped in their empowering of the consumer/survivor voice. The underlying principle required is the same as it was on the individual level: the consumer/survivor voice needs to be heard, and self-identified needs must be met.

As Breton observes, empowerment requires a group to find and express its collective voice. Then this voice must be heard outside of the group.[7]

Judi Chamberlain found that empowerment does not happen to clients by themselves, but as part of a group.[8]

On a systemic level, it is the mental health system itself that needs to recover – it needs to recover its fundamental purpose as a place of healing, support and refuge. It will not do this without the collective voice of consumers and survivors at every decision making table.

At the Centre for Addiction and Mental Health (CAMH), there is an Empowerment Council that represents the client voice on a systemic level. CAMH funds this Council as an independent organization accountable to clients for its direction and policies. As a result of this collaboration between a voice of clients and the mental health facility, a Bill of Client Rights was developed that is the most powerful one of its kind in the country. For consumer/survivor organizations to be able to effect such meaningful change, the independence of these groups and must be protected. Undeniably there can be tension between the empowerment of clients and the protection of the status quo for mental health services and funders. Allowing such tensions to exist without threatening consumer/survivor organizations into silence is the only way the mental health system can itself recover or discover how to best meet the self defined needs of the people it exists to serve.

[*] Jennifer Chambers is the Empowerment Council Coordinator at the Centre for Addiction and Mental Health, Toronto.

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PEER SUPPORT AND RECOVERY: BELIEVING IN HUMAN POTENTIAL

Fiona Wilson[*]

> *Tink was saved. First her voice grew strong, then she popped out of bed, then she was flashing through the room more merry and impudent than ever. She never thought of thanking those who believed, but she would have liked to get at the ones who had hissed.*
>
> -- J.M Barrie's *Peter Pan*[1]

When I was first asked to write this article I asked myself, "what can I say about peer support and recovery that's hasn't already been said?" I don't profess to be an expert on peer support, but am one of an ever growing number of people who have personal experience with the mental health system, values peer support as an emerging evidence based-practice, and continues to advocate for various types of peer support services to be embraced within institutions, agencies and communities. Nor am I an expert on recovery – but, who is? Rather, I consider myself a strong advocate for a movement that supports the idea that each individual who has experienced a mental illness is the true expert on their own recovery process. So, what is it that I can say that is different from anyone else? Then it occurred to me – it is not so much that I need to be different, but I want to take advantage of the opportunity to join my voice with the many others before me who have contributed to the body of thought and literature on both peer support and recovery. I want to challenge a few myths and misconceptions along the way, and perhaps offer my own unique perspective on how peer support, in its various forms, can support and facilitate a person's recovery process.

I believe we are living in a time where the culture of mental health appears to be embracing the demand for formalized peer support and yet, at the same time, is tiring of the use of the term "recovery." In some circles, recovery as a concept is losing its glow. I would argue that this is largely due to the inconsistency in how we have come to understand what recovery means and who should define it.

So what exactly is this thing we call recovery? The literature is weighty in its attempt to define and understand the notion of recovery. It is vast in its efforts to define what best supports the recovery process, what treatments and practices should be endorsed and who should be involved in initiating the process and who decides when it is achieved.

Often, those who provide services are under the misconception that recovery is something they do, that it is part of treatment. Alternatively, there are those who would argue that recovery is something that only the person with a mental illness can experience while utilizing the supports and services of their choice that might help them along their chosen recovery path. Individuals with mental illness clearly distinguish between recovery and treatment or rehabilitation.[2] Indeed, where treatment and rehabilitation might include psychopharmacological treatment, skills training, and psychosocial supports from trained mental health professionals, recovery is seen as separate from these services.[3] Keeping in mind that recovery is a personal and unique experience, the literature shows that when people are asked to conceptualize the factors important to their recovery, common themes emerge, including hope, empowerment, education, control, connection and spirituality[4,5,6] This is not to say that people don't recognize the importance of treatment and rehabilitation to the recovery process, but recovery often means overcoming or minimizing the effects of having been institutionalized, treated and or having received services as a "mental patient"[7] or, as William Anthony[8] suggests, it is growing "beyond the catastrophic effects of mental illness." Indeed, many people come to be defined and stigmatized by their illness and in turn, start to define themselves in the same way, having internalized the beliefs they have heard so often from those around them. Therefore, redefining one's self by discarding a previously illness-dominated identity[9] is equally crucial to the recovery process.

This begs the question of where peer support fits in the recovery paradigm. I am going to resist the temptation to laud the value of peer support in terms of service provision and outcomes related to formal mental health services. The evidence speaks for itself regarding outcomes related to a decrease in formal service utilization, reductions in length of stay, increased capacity for self-determination and meaningful community integration.[10] What is perhaps more important, and indeed more relevant to this discussion, is how peer support facilitates the recovery process as it is defined by those who experience mental illness. How does peer support offer hope, facilitate empowerment, support a change in the locus of control, and encourage connection?

First and foremost, it can be argued that there is no better example of hope then bearing witness to one person's ability to overcome the effects of their illness and redefine themselves than through peer support. Peer support offers opportunities for those who have the shared lived experience of mental illness, and have gone through the recovery process, to be role-models of hope for others, to provide hope in the belief that recovery is in fact possible. Patricia Deegan says the following about her own recovery experience:

> It would have greatly helped me to have had someone come and talk to me about surviving mental illness – as well as the possibility of recovering, of healing, and of building a new life for myself. It would have been good to have role models – people I could look up to who had experienced what I was going through – people who had found a good job, or who were in love, or who had an apartment or a house on their own, or who were making a valuable contribution to society.[11]

The exposure to others, who have managed to redefine themselves despite their illness, is the first step in being able to envision one's own capacity to do the same. Indeed, peer support providers not only act as role-models to their peers but also to mental health professionals who become jaded by their own illness-dominated lens. Davidson et al. argue that there is perhaps:

> No more powerful or direct way to bring about such changes in beliefs about mental illness than to have as colleagues people who have been personally effective in busting apart old stereotypes, and who in so doing provide positive role models for our clients as well as ourselves.[12]

As an individual comes to realize their own potential to begin or continue their recovery journey, they can gain a greater sense of empowerment in their lives. With empowerment comes the belief that one has control in their life – empowerment and control are enmeshed with one another. I believe that one of the first things a person feels they have taken away from them when they are diagnosed with a mental illness is control. The sense of helplessness and dependency that so many of us experience with any long-term illness can be devastating, with mental illness the prevalence of the belief, that people cannot and should not have certain control or decision making powers is expanded. This belief in turn is cultivated by how mental health services are often provided. The peer support relationship, at its very core, is about control; that is, ensuring that it is the goals, desires, and needs of the peer beginning their recovery journey that controls and drives the relationship. Peer support acknowledges that recovery is a personal choice. There should not be any hierarchy in the peer to peer relationship; rather it is based on a mutual understanding of shared responsibility and learning. Indeed the peer helper is as likely to learn and benefit from the relationship as the person being helped.[13]

Hope, empowerment and control do not emerge during the peer relationship in a linear fashion, any more than the recovery process itself is linear. Clearly, hope and empowerment are not mutually exclusive experiences in the same way that empowerment and control are not.

Similarly, connection is a crucial component to the peer support relationship and the recovery journey. Lisa Dixon describes recovery as a "profoundly social process" where people are trying to recover a means of being with other people.[14] For some, the most powerful form of connection is with others who are also living with mental illness. This type of connection not only provides what Dixon calls "validation and reconciliation of their own experiences," but also provides safe and non-judgmental venues to try out a reclaimed or reformed identity and voice. Peer support has been described as "an inclusive model that creates room for all people to fully experience 'being who they are.'"[15] In this way, the role of peer support is not to assess or judge. Rather, the role of peer support is to listen, empathize, and value the whole person regardless of behaviour or diagnosis. Through having access to safe opportunities for connection, a person can feel confident in seeking out other connections with people within and outside the mental health community.

Peer support services do not pretend to "do" recovery. Peer providers can act as exemplars for what recovery can potentially be. I am inspired daily by my peers who live and love despite, or in spite, of their illnesses and the subsequent impact on their lives. I learn so much from others when they share their personal stories and reveal their own unique recovery journey. I equally despair when I hear a telltale sigh or grumble at the utterance of the word "recovery" and continue to wonder what more needs to be done to convince people it is a reality. For some, recovery is like the elusive but magical fairy; individuals who experience mental illness sometimes need to hear a resounding "we believe…we believe" to take flight – and this, without any hitches, is what peer support offers.

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THE ROLE OF MUSIC IN RECOVERY FROM MENTAL ILLNESS

Ed Harrington [*]

The Importance of Music

Music has for many years played an active role in the daily lives of people all over the world. There are many different kinds of music, and the choices of these are almost limitless. Music is often associated with, and included as a part of, special events. When most persons were very young, they may have experienced being soothed by a lullaby from someone who was trying to help them to feel reassured, to relax, and perhaps to sleep. In a great many religious services over the years, singing and instrumental music were, and still are an important part, of the programming.

Music in its varying forms has been known to express love, lost love, hopefulness, hopelessness, happiness, sadness, and sometimes, just plain fun. When we hear a song that takes us back to a special place, special person, or time period, there is something saying to us that this is a wonderful thing and I feel happy. Nothing else matters at this moment.

Many people have stated that music is a source of comfort during times of loneliness. We know that loneliness can be for a short period of time, or for what might feel like an endless duration. During these moments, there may be no one around to talk to. Music can therefore help to fill a void at these times.

Some Observations

During my years as a Patient Advocate working in psychiatric facilities, I was fortunate to have opportunities to provide music to persons who were receiving care and treatment for psychiatric illness in the facilities and in the community.

I was also able to perform music with patients and care givers. One distinct and positive observation was that when someone was listening to or performing music, things such as titles, labels, and status were not important factors at that time. A person who was a patient, singing a song and perhaps playing a musical instrument along with the Patient Advocate and a therapist, was an equal part of the musical group, and their suggestions or criticisms were readily considered.

Some facilities have provided music therapy as a program that patients could choose to participate in if they wanted to do so. Comments that have come from individuals who attended music therapy sessions were usually very positive.

Several psychiatric facilities provide music on a regular basis in a number of different ways. In some cases, regular social events provide a good variety of music. Patients and staff may be invited to participate and perform songs during the event. This kind of participation appears to have a positive impact on participants, as well as those who may not participate but get a great deal of pleasure from the music.

Persons who were patients in the psychiatric facility often expressed their appreciation for the music presented for special events at such times as Christmas, Easter, and Thanksgiving. Memorial services for patients and staff were also always well attended, and everyone appeared to feel comfortable and comforted by sharing in the musical portions of the services, while also sharing emotions at these times.

The importance of music as an integral part of programming for persons receiving mental health care was observed by this Patient Advocate in a psychiatric facility in Northern Ontario during summer camp planning. Transportation was arranged for inpatients, as well as for outpatients from the community, to attend a lakeside camp where musical activities were provided for everyone during day and evening program planning. The relaxed atmosphere, along with the sheer joy and pleasure of listening and partaking in the music, were evident on people's faces, in addition to the many compliments and statements of appreciation we received.

Music in the Lives of Seniors

There are a great many musical programs provided on a regular basis in psychiatric facilities, as well as community residences for seniors. In speaking with senior residents and staff in these settings, I was told that these seniors look forward to the musical sessions because they enjoy the music, and because it also helps them to remember and to reflect on past events, places and persons who were important parts of their lives.

Indeed, I have observed seniors during musical programs singing, tapping time on a table or a chair, and at times shedding a tear because a particular song has touched their heart and brought them a short period of happy memories during their day.

Therapists and Music

Fortunately, there are a number of therapists who feel that music can provide a great deal of comfort, support, and confidence for persons coping with mental illness. In some cases, it may be felt that during the persons' recovery, music should be made available to them, and encouragement offered to the person, especially where music was an important factor in their past. I have known therapists who took active roles in assisting clients with musical backgrounds acquire or have access to musical instruments, or making arrangements for the acquisition of an instrument for a client. For persons with a musical background, the benefits of music may be lasting, and very much appreciated when made available.

Once I entered a ward in a psychiatric facility and heard a most beautiful piano melody being played. I was drawn to it and discovered that a patient was playing the melody. I expressed my enjoyment at hearing the piece, and commended the person on the excellent command of the piano. She informed me that for years she had been a classical music student, and wanted someday to continue with music where she had left off before having been hospitalized.

Music and Moments

Since music is a personal choice and everyone has different tastes, there is a great deal of freedom of choice and independence attached to it. A person should be able to choose a radio station that meets her/his personal needs at any time, day or night. This could be at home, while walking, exercising, or while working.

Many people returning to their homes in the community after hospitalization may spend a great deal of their time alone. Even though there are support programs in place in many communities, music can provide a source of comfort and enjoyment when no one else is around.

Of course it would be very difficult to determine just to what degree music might be a factor in the recovery of persons with mental illness. However, I believe that statements from persons who have experienced mental illness, and from persons providing care and treatment for mental illness, support the fact that music can be an important part of a total program of therapy, and that music as a part of the program may be of great help to many on their journey to recovery, and productivity in their communities.

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[*] Ed Harrington is a former Patient Advocate with the Psychiatric Patient Advocate Office and an avid musician.

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FRIENDSHIP AND RECOVERY

Jennifer Ottaway[**]

I once studied sociology and wrote a term paper on friendship. The professor found the topic unworthy, my paper got me very low marks and my enthusiasm for the subject floundered. It was one of those required courses in an arts degree. Thanks to friends and family and other encouragements, I finished university and enjoyed most of my courses. I was working through a major in physical education; teaching outdoor education was my aim. I put an 'X' through the further study of sociology. Maybe the ideas fit my studies but my treatment of the topic was just not scientific enough.

I am no scientist but I know how important friends are in one's life. Friends, strangers, parents and my own children saved me many a time, especially during periods of soul searching and more recently, divorce. I chose January 2000 to leave my "perfect on the outside" family to strike out on my own – that January when everyone expected a disaster.

This disaster was of my own choosing. I had a great desire to be me, to follow my dreams, to get out from under the dictates of my well-meaning husband, to open a centre for families in difficulty. This takes training, money, backing and guts. It turned out to be an unpopular choice; my husband rallied family and friends to try to make me see 'reason,' to protect our assets and to make money. But, from 2000 to 2004, I was my best friend, mostly alone, often homeless, of no fixed address, living out of a backpack and at shelters for women, experiencing a made to measure training-and-study class in sociology for those families in difficulty. Of course, the irony of it all: we were the family in difficulty. Has any of my family acknowledged that yet?

For me, the studies continue. My on-the-street training was a tough haul that has paid off. The once important family and friends circle shifted considerably through the divorce. Economic restrictions put me on skid row. Divorce laws are not kind and have little respect for social standing. I had no debts when I separated from my husband. My father, at last count, was a millionaire and I was raised as a responsible citizen. Those shelters and charities to which I once gave donations became my shelters and ports of call. Forcibly I met many new friends – buddies in hard times on the streets, people of all ages in soup kitchens, in prison, through conversations with staff and clients of women's shelters in many towns and cities across two provinces – as I searched for a new home. Now I own a farm, Gîte Le Grand Détour, where I can take in people, singly or as families, for respite and T.L.C.

The connection I have to the Psychiatric Patient Advocate Office (PPAO) is one of friendship. I was not institutionalized long enough in Ontario to receive official help but I occasionally write to David Simpson, Program Manager. He encourages me to write, paint, express my views and advocate for my rights.

I saw a notice on a bulletin board about the existence of the PPAO as I was calling friends on the public phone in a big, scary institution on the evening of my having been whisked away by the police for a psychiatric evaluation. A happy note in troubled times.

Court and medical orders had been signed in May 2000 but I was the last to know. My adolescent children were instructed to keep me busy in our neighbourhood while the police arrived. I had come to the area to treat my son on his birthday. The officers were polite. I kept calm and tried to make sense of the 'event' yet I seethed inside. At the facility, I was frisked, relieved of my shoelaces and glasses, was interviewed and offered a bare plastic mattress on the floor of an empty room … if I wanted to rest. There was a sandwich for supper and a drink while I cooled my heels that hot spring day.

I started asking questions of the admitting physician, a man I happened to know. From what I gleaned, I had been put in a safe place on medical orders; safe from myself, safe from the different lifestyle I had chosen and from the new friends I had made as I navigated the waters of separation, relocation and divorce.

I was in the process of relocating from the city where my family lived as it had become uncomfortable and too small. Some friends I was leaving were willing to listen to me but no one was too happy to have me stay overnight. How many of the happily married, with calm lives and well behaved children, want to talk about your divorce problems, especially those connected to mental health issues? It's about as acceptable as leprosy.

Happily, the hospital staff let a new friend visit me within the hour of my admission. Roger had witnessed the police escort, had followed us in my car as he had no license, no supper, no friends in my old town and I was in a state of panic. He ate most of my sandwich. It was sticking in my throat anyways.

I knew my rights. I had spent many hours, days and years tending to my mental health and questions of diagnosis, counseling and healing. I had read the laws about the dangerously sick and the descriptions of a variety of mental illnesses. Reading in doctors' waiting rooms and working on projects to provide basic care for the homeless - as a member of groups Toronto Action for Social Change (TASC) and Homes Not Bombs- I had come upon the laws and accommodations applicable in Ontario at the time.

Labeling was something my husband had questioned; it scared him to have a sick wife whose energy and enthusiasm for life had waned. We borrowed books from the library; I on the downfalls of codependency, he about bipolar depression and later a child's guide to mental illness. I had been in a depressed state for two years, had looked for help in many ways, all the while consulting our family doctor and following the suggestions.

I was feeling and getting much stronger. It was 1999. What were the stresses in my life at that time? The death of my mother (the progressive loss of her health had kept me busy for many years), the arrival of our children at adolescence and the struggles to run a business with a cantankerous spouse. I had the resolve to get on with my own projects, to help others by investing in a not-for-profit property and enterprise. Unfortunately this was not in tune with my husband's retirement savings plan. I gave him an ultimatum – marriage counseling, therapy and progress or divorce.

January 2000 and I had packed my bags and moved out of the matrimonial home. Wanting to cooperate and keep the peace in our couple we went to one psychologist friend to ask for a standard test of mental health. I apparently "failed" but was not told of any diagnosis. I followed orders to seek more help, met with more specialists until it was suggested that I take medication to "calm me down." I refused, let my husband know this and suddenly many more people became involved in my state of health who held the opinion that I was unfit to make any decisions, never mind seek divorce. I left town.

And this is where my therapy of writing began. I sent off letters to any authority I could call on and kept notes about the events of my days. Some were scribbled on bank receipts or any scrap of paper taken out of recycling bins and found on restaurant trays. I was creating journals that combined painting, writing and collages – great, portable therapy. Coupled with my search for advocacy, these dormant skills became ones of primordial importance. David Simpson got a painting of the street sign of a run down motel I often stayed in when I could afford the treat of a room of my own – a patchwork sign noting a different level of society than that I was raised in, yet that of a small oasis in a suburb of Québec City. My lawyer was willing to take paintings of the St. Lawrence River valley in lieu of payment as he realized I was out of money. And Québec is where I have since chosen to live, where friends invited me to stay. Once the divorce was hammered out, I bought 80 acres and a 200-year-old house and farm buildings - to share. My style of outdoor education is offered for all who wish to come participate in a family style project on the beautiful island of Orléans.

Perhaps this is a fairy tale. I work to tell the complete story, especially to my children (when they are ready to listen) and offer workshops on the importance of following one's dreams. Cinderella, the renegade in hiking boots, worked in strawberry fields to pay for a few luxuries and ate in soup kitchens for four years. In those days, when the legal system allowed a woman who owned five houses in a tiny corporation (using her name as title) to be stripped of bank accounts, to have had all her assets frozen, to be threatened with the suspension of her drivers' license if she was not following a prescription for medication, was allowed a sum to last her a year and had no idea that the divorce process would last four…. she became an artist of greater resolve. And one to do some advocacy of her own.

[†] Thanks to all the players in this tale. I hope that some of the social workers and psychiatrists involved will recognize my name and look me up. My daughter, happily reunited with me, announced that I could be found through 'Google.' The media attention for this 'rags to riches' reverse story has helped me get my artwork and writings into documentaries and magazines.

[*] Jennifer Ottaway is a concerned citizen who has devoted her life to working on issues of social justice. She lives and works from her farm near Québec City, where she lives best.

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THE JOURNEY IS HOME[1]: HEART, MIND, SOUL, STRENGTH, AND STORY. PERSONAL REFLECTIONS ON SPIRITUALITY AND MENTAL ILLNESS

Meredith Hill*

I'm a preacher's kid. As a three year old, I heard my parents discussing which church-folks were coming to dinner, and I chirped in, "Don't forget to ask the Holy Ghost!" Perhaps that's only a "kids-say-the-cutest-things" story. However, in reflecting back over the sixty years since then, I see three elements about myself: confidence in an always-present faith community; comfort with traditional Christian language and imagery; and certainty that welcoming a spiritual dimension into daily life is just what we humans do.

These elements were gifts of my family heritage. I also received a familial trait of mental illness, episodes of clinical depression observed and untreated in earlier generations, present and variously treated in all four siblings. Add violence and abuse to the mix.. Combine with it a lifelong affiliation with the institutional church, which has proven to be a source of both joy and suffering. My experiences of depression had many contributing factors. Nevertheless, those three gifts embodied in my invitation to the Holy Ghost have been crucial on my "crazy path to wholeness."[2]

"Church" defined *everything* in my childhood home; not only was God was my father's boss, the institution employed him and owned our houses. Services, Sunday School, youth groups, junior choir, and pot-luck suppers filled our calendars. On one hand, Church was an institutionalized religion with a program of activities, a belief structure, rituals, specialized leaders and loyal followers.

But on the other hand, Church was a carrier of spirituality when it spoke of individual meaning and essence, calling and purpose, relationships with self, the world and God, sacred creation, hallowed places and grace-filled people. These ideas were positive gifts to a young girl's maturing heart.

However, with Church as the unseen guest at every family meal, my heart could also perceive its darker side: oppressive power dynamics, hypocrisy, a stifling agenda of rewards and punishment, pride as possessors of truth, narrow-minded judgments, and plain old human weakness.

Forging my own individuality in the face of this all-defining identity meant leaving the Church in my 20s, with hopes of finding a new path. But my 30s saw a return to Church to baptize my sons. Once again, study groups, refugee work, and worship committee meetings filled my calendar. They also began to fill my mind for I got hooked on reading theology and enrolled at a seminary with the intention of studying, and studying only. Even fuller immersion into institutionalized religion began and within one short decade, I was a priest.

That decision was not primarily a matter of mind. Theological studies require you to walk deep into your soul, searching for meaning, purpose, identity, and direction. And you get to do this soul work within a community. A meditation group, retreats, and daily time in chapel support that spiritual path. This was true through two serious encounters with depression – profound dislocations that meant leaving school to focus on therapeutic work, self-care, and medication adjustments. Still, I had a community to which I could return, at least for a time.

My professional connection with the church did not survive finding, loving and committing to a new life-partner, a woman, and the bishops' decision to suspend my license as clergy because of that. It did not survive the diocese's refusal to pursue an abuse complaint against my father because it had been familial and not in a priestly capacity. It did not survive serious descents into the dark hole of depression, some situational and reactive, some a dreaded familiar return.

Thankfully, earlier steps along the journey had given me resources for more soul work and healing. I had therapists willing to work with my faith-community's language and imagery. I had a new partner whose creation-based spirituality spoke volumes. And I had a radical, politicized, justice-seeking congregation willing to let me rage and disappear and then welcome me back and invite me to celebrate communion or preach

Preaching takes all my heart, mind, soul and strength. To proclaim love, compassion, hope, justice, forgiveness, grace and peace, I must enter into the story and meaning of a biblical text. I must look, with all the compassion and clarity I possess, at the darkness, suffering, pain, alienation, isolation, bleakness, and brokenness that can be addressed by the loving, sacred Ground of Our Being who longs for our restoration to wholeness. To proclaim that truth requires first the strength to seek it. Gradually, I could begin that search confident in my strength to keep going.

The little girl who invited the Holy Ghost to supper became a woman whose encounters with the sacred have often been every bit as concrete. A metaphoric parallel between that dinner party and the Lord's Supper is almost immediate given that the language and imagery of the Christian tradition had been absorbed from birth. Biblical and theological concepts that are in my blood attached themselves to incidents and places. Often an object, a concrete thing, was part of such events and became iconic in that it enlarged my awareness of the sacred, the holy, the divine …God (if you will). The amazing thing was that icons were present time after time for me.

At a college retreat, a group of us used fabric bits from my sewing scrap-bag to create a mural. From the silhouette of a blasted lifeless tree, there emerged a vine with riotous blooms moving through a golden satin circle. Our image spoke of our hope for health and liveliness to emerge from all that is barren and dead to create an inclusive, celebratory faith community. We were praying through that image, praying for the rebirth of ourselves and of the church. Not surprisingly, we later mounted that mural in our meditation group's meeting room.

The ordinary and extraordinary kept coming together. One dark winter I took up needlepoint, used an image doodled in class, and poured myself into the stitching. Shades of red surrounded a womb-like shape, which seemed to awaken, transformed into a new reality. Amazingly, my professor accepted the needlework and my reflections on it as a study of Paul's oft-repeated phrase "in Christ."[3]

Another dark encounter prompted an image of being entombed deep inside a cave and the question was "Who will roll away the stone?"[4] The women followers of Jesus asked this question as they approached his burial place with ointments to honour their friend's violated body. My ordination-day gifts included a drawing by a Japanese artist of three women in mourning, coming to perform that task. Quiet time spent with that small drawing taught me much about friends' love and care, and about moving from a cave of death and darkness back into light and life.

My most serious battle with depression required hospitalization. In the entrance to Women's College Hospital in Toronto stands a striking, tall, womanly statue – representative of all the women who have dedicated themselves to this place of healing. Simply standing beside the statue became my daily spiritual practice. For me, it became the feminine face of God giving comfort and peace. Its inscription reads "*Non quo, sed quo modo*," words first used at Women's College on the pins of its nursing graduates. It translates as "Not what we do, but how;" that is, our selves are not so much defined by what we do as by the manner in which we do it, the "how" of our living, the way we are in our world. The earliest people who responded to the gospel were called followers of "The Way." That mothering statue both embodied and pointed me towards a new way

Part of that newness was our move to a home with a riverbank and three acres of forest, meadow and gardens. "And God saw that it was very good."[5] I came to believe that living in such sacred space changed me in some organic, bodily way and to say I became a new person had a double layer of meaning. We called our new place "Consider the Lilies"[6] for this biblical instruction is an assurance of bounty and goodness that far outshines Solomon's splendour. There had been a new awakening, and I gave my home an iconic lily.

But the "black hounds of hell," as depression has been called, returned; that return showed me that my journey did not have a destination point. Rather, I had to struggle, re-learn and finally accept that the journey itself is home, a place of setback, sorrow and challenge, and one of growth, grace and healing. Depressive illness is part of who I am, but it not longer defines how I will be in the world. There are still professional caregivers in my web of supports, but their role diminishes as meaning-making clarifies and as I engage more fully in intentional spiritual practice.

These days I have an early walk which daily gives me the sacrament of dawn; a meditation group which enhances contemplative times alone; a parish-based theological study group which gives me great new books and opportunities to facilitate discussions; volunteer work in a hospice which lets me walk with the dying and the bereaved in their very sacred space; extracurricular work in a high-school Gay-Straight Alliance which enlivens my heart with young people's passion to change the world. I could not ask for a better home than the current journey.

*Meredith Hill is a psychiatric care consumer and spiritual sojourner. She continues to be a parish member and Honorary Assistant at the Church of the Holy Trinity in Toronto while also teaching English at Crestwood Secondary School in Peterborough.

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2 Jan Sheppard. Workshop Title, 3rd International Conference on Spirituality and Mental Health, St. Paul University, Ottawa, Ontario, May 3, 2007
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4 Mark 16:3.
5 Genesis 1:31n.
6 Matthew 6:28.

WOMEN WITH DISABILITIES – DAWN ONTARIO

Marianne Park*

When I was approached to write this article for this landmark publication, I was thrilled. I enjoy writing as a hobby, but my excitement came from the fact that disability was being acknowledged at the outset. Far too often the unique perspective of women with disabilities is overlooked or viewed as an add-on. Set in a historical context, women with disabilities were not really on the radar of society and mental health was something that was not discussed 25 years ago.

I am pleased to serve on the Board of Directors for DisAbled Women's Network Ontario (DAWN Ontario), a progressive volunteer driven feminist organization promoting social justice, human rights and the advancement of equality rights through education, advocacy, research, coalition building, resources development and information technology. DAWN Ontario is the only provincial feminist cross disability organization in Ontario providing leadership in advocating for inclusion and equality for women with disabilities. We operate without funding.

Although a 2005 study by the Ontario Women's Health Council[1] did not list women with disabilities as having higher rates for depression than temporarily abled women, other studies such as one conducted by the Center for Research on Women with Disabilities Baylor University in Houston Texas[2], concluded differently. The early seeds of depression in those of us born with disabilities are planted by the experiences of "searching" for a cure to make us normal all in the name of parental love. The seeds are germinated by the schoolyard taunts lobbed by bullies looking to exorcise the demons in their own minds covering up their own insecurities by making others feel inadequate. For women who become disabled, a great amount of time, money and energy is spent trying to get back to the way they used to be. They often experience great isolation and relationship decline as people will focus on how they used to be rather than living in the moment. Day after day, women with disabilities are presented with the societal message that they do not belong. We are not often reflected in the media in a positive way and, in fact, we are made quite invisible. This and other experiences allow depression to thrive. Our society expounds a great amount of resources looking for a cure rather than focussing on quality of life. Disability is not an exclusive club; anyone can join at any time.

The depression stems from the multitude of barriers we encounter. We reside in a society which is quite inaccessible, both physically and attitudinally. We experience higher rates of abuse and fewer opportunities to access general and reproductive health care. Women with disabilities are often referred to as being in double jeopardy. At times it is difficult to know when you are marginalized: is it because of your gender or your disability – one cannot be easily separated from the other.

Poverty is the one inescapable reality for women with disabilities. We have a 74% unemployment rate. The medium employment income for women with disabilities is $8,360.[3]

Violence is another reality for women with disabilities. As a woman with a disability, I am one and half more times likely to be abused[4]. It is well documented the role violence plays in mental health[5].

Technology, although expensive, has been a lifesaver for many women with disabilities. Through the listservs operated by DAWN Ontario, countless women have found support, empowerment and the tools to advocate for themselves and others. We have also very effectively distributed information about many social justice campaigns including, Ontario Needs a Raise, Step It up 10 Steps to End Violence against Women and many more.

DAWN Ontario acknowledges that networking is our strength and we are pleased that the Psychiatric Patient Advocate Office includes us in their network.

*Marianne Park is a board member of the DisAbled Women's Network of Ontario (DAWN), a board chair of the Income Security Advocacy Centre and Vice-Chair for Echo-Improving Women's Health in Ontario.

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[2] Center for Research on Women with Disabilities, Baylor University, Depression and Rural Women with Disabilities, 2006.

[3] Statistics Canada and Massada and Ridington, *Meeting Our Needs*, DAWN Canada, Health and Activity Limitation Survey, 1992.

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THE HUMOUR R_x: WHEN MENTAL HEALTH IS A LAUGHING MATTER

David Granirer*

When you're coping with a mental illness sometimes your thinking is a little delusional. Some people think they are the Prime Minister or God. Me, I think the Leafs will win the Stanley Cup.

Stand Up For Mental Health comic Allan Strong

Most people think you have to be nuts to do stand-up comedy. And as a counsellor, stand-up comic, and someone with depression, I agree. That's why in 2004, I founded *Stand Up For Mental Health*, an organization teaching comedy to people with mental illness as a way of building confidence and fighting public stigma.

Many people with mental illness suffer from crippling shame, feeling flawed and hopeless because they are not "normal." They often spend years hiding their mental illness for fear of being ostracized and shunned. Sometimes they just give up on life and stay mired in poverty and isolation. It's a huge waste of their talent and potential as human beings, and costs our society hundreds of millions of dollars in lost productivity (especially when you consider that one in five people will be diagnosed with a mental illness during their lifespan).

But teaching them to do stand-up comedy about their mental health journeys has an amazing effect. Often for the first time in their lives, students embrace the word *crazy,* and learn to laugh at their mental illness – and their audiences are laughing right along with them. They have discovered a talent they never dreamt they had.

The program is a lifeline for those who take it. We've heard them say more than once, "This has given me a reason to keep living." We've also seen people who have done nothing but smoke and watch television for 15 years become re-engaged in life and make healthy changes so they can stay in the class and keep performing. The fact that people with mental illness can succeed at something that most so-called "normal" people would never want to try is a huge boost to their self-esteem.

Stand Up For Mental Health is also incredibly cost-effective because every dollar serves a dual purpose: recovery and rehabilitation for the comics *and* raising awareness and fighting stigma in the general public.

An attendee at one of our shows said that two years from now she would not remember what some "expert" on mental health had said, but that she would never forget the show that our "mental health consumers" gave. Let's face it – many people don't want to hear about mental illness because it's too much of a "bummer." But when the message is delivered through comedy, they're a lot more willing to listen.

Though I started the program in British Columbia where I live, Ontario has embraced it. Currently, we have a program in Toronto run by Michael Cole through the Mood Disorders Association of Ontario (MDAO), which is committed to helping us spread the program throughout Ontario. We have a program in Fort Frances in conjunction with MDAO and the Canadian Mental Health Association. In Guelph, there is a partnership with Spark of Brilliance, Janssen-Ortho, MDAO and the Canadian Mental Health Association-Grand River Branch. We are also working with the Psychiatric Survivors of Ottawa in Ottawa. Finally, we are in Peterborough in partnership with the local Canadian Mental Health Association.

In Guelph and Fort Frances, we're pioneering the use of technology to deliver classes. I run these classes from my home in Vancouver via conference calls and speakerphone. Plus, I fly in several times a year to do shows with the groups.

Although we have lots of anecdotal evidence about how the program helps people, so far we have no research data. But that will soon change. We have a partnership in London with Canadian Mental Health Association-London-Middlesex, WOTCH Community Mental Health Services, and researchers from the University of Western Ontario (Dr. Abraham Rudnick, and Dr. Rod Martin), and York University (Dr. Paul Kohn) to do some research to see exactly what the program does for our students.

Though unproven, I have some thoughts on why doing stand-up comedy has such a powerful effect on consumer/survivors. First of all, when people are part of *Stand Up For Mental Health*, they identify as comics, not as patients. Let's face it – it's way cooler (and better for your self-esteem) to tell people, "I'm off to stand-up comedy class," than to say, "I'm going to my personality disorders support group."

People in our program immediately attain what we performers refer to as a "high-status" identity. Because they're doing stand-up comedy, others see them as courageous, funny, and talented, not broken or sick. Since much of our self-image is influenced by what is reflected back at us from others, doing stand-up comedy changes how our comics perceive themselves. Imagine for the first time in your life having people admire you and tell you they think you're brave and funny. Imagine having mental health professionals say to you, "I could never do what you're doing." Imagine finally being able to talk about your mental illness and have people eagerly listen to your every word. Imagine getting standing ovations.

Also, doing stand-up comedy creates a cognitive shift. Many of us with mental illness carry shame from times when we've been hospitalized (sometimes against our will) or behaved destructively or inappropriately. In *Stand Up For Mental Health*, these experiences become great material. Instead of trying to forget these past episodes, our students gleefully dredge them up to use in creating their acts. In other words, these sources of shame are transformed into strengths that help them excel at comedy.

This cognitive shift also changes how students deal with present setbacks. While she was in the program, a student split up with her husband. Normally she would respond to this kind of situation by isolating and beating herself up. This time she came to class determined to make the break-up part of her act, and came up with some hilarious bits. Instead of falling into an old pattern of seeing her break-up as confirmation of her unworthiness, she saw it as an opportunity to create comedy.

In order to help create closure or empower their clients, some therapists have them take painful incidents from the past and "rewrite" them, changing the ending or allowing themselves to say things they wished they had said at the time. The same thing happens in stand-up comedy. Take this joke by Keri Aitken-Toby, one of our Guelph comics:

> *I've been in the psych ward, and you have to question the way they treat you. When you're paranoid, the last thing you need is to be interrogated by people in lab coats, then placed in a room with a surveillance camera. I'm thinking, "If I wasn't paranoid before, I sure am now!"*
>
> *And then if you keep acting out they call a code white where a team barges in and restrains you. Now I love having a bunch of guys hold me down just as much as the next girl…*
>
> *But I at least expect to be taken to dinner first.*

In this joke, Keri transforms herself from powerless victim to victor because she, not her oppressors, gets the last word. And telling it to a laughing, applauding audience of 200 people further validates this transformation, greatly magnifying the effect she would get in therapy by telling the new version of the story to one person or a small group.

Why this intensified effect? When two or more people laugh at a joke, they communicate that they share the world-view and experience of the joke teller. In other words, it's like the listeners are saying, "We're totally with you." Other than doing stand-up, I can't think of another kind of therapy where you get to have that experience with hundreds of listeners enthusiastically cheering you on.

Doing stand-up comedy is also what I call a form of "stealth" psychosocial rehabilitation. To do stand-up comedy, our students have to leave their homes, take public transit (to class and shows), work together, interact with others, meet new people, and develop social skills; all of which we try to get them to do in psychosocial rehabilitation. However, I believe that these activities are easier to undertake when they occur naturally as a by-product of the class, versus as a form of "therapy." Also, most of our students are motivated to push through their resistance to change because they really, really want to do stand-up comedy.

What I've learned from five years of running *Stand Up For Mental Health* is that when we present people with mental illness with a pursuit that captivates them, they will overcome enormous obstacles to participate. Though certainly not for everyone, stand-up comedy offers certain people a unique route to recovery. I look forward to the day when it's a widely offered form of therapy. I think we could all use the laughs!

*David Granirer is a counsellor, stand-up comic, and author of *The Happy Neurotic: How Fear and Angst Can Lead To Happiness and Success*. His program, *Stand Up For Mental Health*, was featured in the CBC documentary *Cracking Up*. Additional information about *Stand Up For Mental Health* can be found at www.standupformentalhealth.com.

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MENTAL ILLNESS AND POVERTY: THE CHICKEN OR THE EGG DEBATE

Pam Lahey*

No one is immune to poverty. In fact, a national poll indicates that almost half of all Canadians feel they are just one or two pay cheques away from being poor.[1] Poverty can become a reality for anyone when one or more unfortunate life events, such as job loss or divorce, results in a loss of income to purchase the basic necessities of life. If this situation continues it can result in poor mental health. The good news is that poverty is usually a temporary situation. However, for individuals with serious mental illness, poverty is often persistent. Additionally, the pathway from mental illness to poverty is not as easy to identify. As a result, creating sustainable ways to prevent poverty from affecting people with mental illness requires a different set of strategies.

People with mental illness who live in chronic poverty often face significant and unique barriers that make it more difficult to secure and sustain access to essential resources. When addressing solutions to poverty for persons with serious mental illness, it becomes imperative to adopt a more socially inclusive definition of poverty – one that takes into account the resources needed to support recovery. For this reason, the Canadian Mental Health Association – Ontario (CMHA – Ontario) adopts the broader definition of poverty used by the Policy Research Initiative: "Poverty involves more than just income deprivation. It can also extend to (or result from) exclusion from essential goods and services, meaningful employment and decent earnings, adequate and affordable housing, safe neighbourhoods with public amenities, health and well-being, social networks, and basic human rights."[2]

Individuals with serious mental illness are frequently unable to access community services and supports due to stigma, gaps in service and/or challenges in identifying and accessing the appropriate resources. Lack of sufficient primary health care and community mental health services, shortages of affordable housing, and inadequate income support can further alienate individuals from life in the community. Exclusion from these social and economic supports results in social isolation, significantly increasing the risk of chronic poverty. Additional supports, specifically in the area of education and employment, may also need to be put in place in order for individuals to maintain the necessary resources.

Poverty is commonly assessed by comparing an individual's income with Statistics Canada's low income cut-off measures (referred to widely as the poverty line.) If you are below this line, then you are considered to be living in poverty. According to 2006 low income cut-off figures, an individual living in a mid-sized community is living in poverty if their income is less than $1522 per month. By this measure, individuals on social assistance, as well as those who work full-time at a minimum wage job, are considered poor. Many people with serious mental illness fit into one of these categories.

Individuals with work-limiting disabilities are nearly three times as likely to be poor and four times as likely to be in receipt of social assistance as individuals without a disability. In 2006, one in three recipients (77,430 people) of the Ontario Disability Support Program (ODSP) had a serious mental illness.[3] Yet at $999 per month, ODSP rates are significantly lower than what is needed to cover the cost of basic necessities, such as food, clothing, and housing. Furthermore, while waiting to be granted ODSP benefits, a significant number of people with mental illness are on Ontario Works, the publicly funded income support program for those in temporary financial need. Ontario Works recipients receive only $554 per month, roughly half the amount provided to ODSP recipients ($999). So, Ontario Works recipients experience the most extreme depth of poverty, living on incomes that are 64% below the poverty line![4]

Occasional increases of 2% and 3% will not alleviate poverty for people who rely on public assistance. Even the most conservative think-tanks in the country are in favour of enhanced assistance for those on disability benefits. In such a wealthy country as Canada, a more humane solution would be to increase social assistance rates to levels that reflect the real costs of living. This means expanding the current level of benefits to include: sufficient money for market rental accommodations (according to region); adequate income to purchase a nutritious food basket as suggested by public health departments; and money to cover utility costs, transportation costs, and the cost of interacting with one's community. This new benefit level must also be indexed yearly to keep pace with the cost of living.

Safe and affordable housing is pivotal resource to a person's recovery. It provides the stability required to pursue other activities, such as employment. Housing costs have continued to rise since the 21.6% cut to social assistance in 1995 and are now much higher than they were during the mid 1990s. The 2001 Census data indicates that 42.2% of Ontario renters are spending more than 30% of their income on rent. In addition, rent supplements and public housing are available to fewer than half of ODSP recipients, leaving the majority of recipients paying full market value for their rental housing.[5] This leaves little or nothing at the end of the month to cover the cost of nutritious food, clothing and other necessities. More affordable housing is clearly part of the solution to alleviate poverty for persons with serious mental illness.

Affordable housing sets the stage for stable employment. However, persons with limited education or outdated job skills often remain trapped in low-income jobs that perpetuate the cycle of poverty, further blocking their access to necessary resources. For people with mental illness, the likeliness of being trapped in low-paying jobs increases because mental illness can seriously interrupt a person's education and career path, resulting in diminished opportunities for employment. In the case of individuals with mental illness, lower levels of education may be attributed to the fact that mental illness often strikes in adolescence and early adulthood, when formal education usually occurs. Interruptions in education have consequences that reduce opportunities to acquire better jobs. To provide the accommodations and supports adult learners need to achieve their educational goals, opportunities need to be expanded to include supportive education programs. Equitable access to skills training reflecting regional workforce needs is essential. Money to take advantage of these opportunities must also be made available for persons with mental illness.

Career development and long-term employment interruptions are common for persons with serious mental illness, resulting in a higher rate of unemployment (relative to those without a mental illness) and difficulty in retaining employment. According to the Canadian Community Health Survey, 30% of people with a diagnosed mental illness in Ontario did not work in 2003.[6] Employment is central to recovery for many people. Supportive employment programs that allow for incremental success in achieving sustained employment in a competitive workplace have been shown to be effective in integrating persons with mental illness into meaningful employment. More investment in these types of programs is needed. Workplace accommodations have also been shown to increase the likelihood of successfully finding and keeping competitive employment. Accommodations such as providing an employee with a flexible schedule (to accommodate the effects of medications), providing work instructions in writing (as opposed to verbal instructions), allowing more frequent breaks or providing the option for part-time hours can increase the retention rate of persons with mental illness.

Yet, work accommodations, while valuable, are not enough to sustain employment. The reality is that low-income earners cycle back and forth between low-paying jobs and social assistance. To put an end to this poverty treadmill, work needs to pay enough to provide for all essential needs (such as housing, clothing, food, and transportation). One strategy that has garnered much support in the social justice realm is an increase to the minimum wage to a level that provides for a decent standard of life. Advocates have set this range at $10.00 to $11.70 and argue that it must be met immediately. Without a secure wage, an escape from poverty is unlikely.

Poverty results in exclusion from community life. Lack of money prevents individuals from taking part in family functions, and denies them a night out at the movies, or a new pair of pants to attend job interviews or social functions with dignity. In short, it denies them the resources many of us take for granted as a social right. Reducing poverty for persons with mental illness will mean assisting them obtain the resources needed for a decent quality of life. Equality of resources should be afforded to everyone.

[*] Pam Lahey is a Community Mental Health Analyst with the Canadian Mental Health Association – Ontario.

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MAKING ENDS MEET: LIFE BELOW THE POVERTY LINE

Rose-Marie Fraser *

A worker's perspective is one that is not often heard, among the voices speaking on behalf of the services and agencies that compromise the mental health system. As a social worker who works with people who are involved in the criminal court system, I have a unique perspective on what is happening in this busy corner of the mental health world. Currently, I work with a unique outpatient program which serves people with mental health issues who have involvement with the criminal justice system. The program is located within a general hospital. There are three consulting psychiatrists, two social workers, two housing intensive case managers and one case manager. The main services which this program provides are psychiatric assessments, social work assessments, counseling, anger management, and more. There is also a medication clinic for those who require intra-muscular injections. Although it is an office-based program with community case managers, it covers quite a large spectrum of programs and works with hard-to-serve clients, clients who are striving for independence.

I would like to start by talking about money, because I think money — who has it, and how it is spent — is an important indicator of what is happening in society. On the scale of health care professionals, my salary is pretty good. Most of my clients, however, are not so fortunate. They are living closer to the poverty level. The cost of living in Toronto has increased significantly over the past few years and people, especially newer Canadians, often have a tough time making ends meet. If they are on social assistance or disability support, they are even lower on the economic ladder.

The recently advertised problems going on with the global economy, described variously as "sub-prime mortgage crisis," "credit crisis" or "global liquidity crisis" have caused me to reflect on how these broader economic factors have systemically impacted my work environment; and, in turn, the work that I do with my clients.

The ever-expanding markets of global multinational companies have fed a frenzy of cost-cutting and profit seeking in all areas of our economic lives for several years. Not only is it necessary to make a profit, but these companies require *better* profits than they earned last year in order to satisfy investors.

A similar process has been at work in the economics of public health funding. In mental health, it seems programs are being measured according to their "productivity" in serving clients. This usually means offering an ever-expanding menu of services to clients, delivered by staff whose qualifications are increasingly generic, and whose skills are focused on the management of illness, rather than individual client needs. Managers are rewarded for keeping within budget, and criticized (or worse) for overspending.

Why do hospitals or community agencies have to fall under the same rigorous budget guidelines as the private economy, where dollars and cents determine the criteria for success? One of the reasons, I think, is related to the impact of the economic system on the mental health professions. Nursing, social work, and occupational therapy all seem (more than ever) wedded to the "medical model" of psychiatry which is in its essence diagnosis-driven, and sanctions medication as the first (and necessary) line of treatment. Since it possesses more economic power (as it is affiliated with big pharmaceutical companies and the rarefied university research environment), and embodies medical authority, the model of biological psychiatry undercuts the holistic orientation which these other professionals theoretically espouse. Workers spend less time speaking with clients and more time inputting data into their computers, or participating in a seemingly endless schedule of a series of doctor dominated "team" meetings. The result is that our work is measured by the money managers, and not by our own professional standards. The academic elites of these professions find a hospitable reception in the corporate-funded corridors of the universities.

One of the assumptions of the *Putting People First* and *Making it Happen* documents was that services aimed at treating and supporting the people with mental health issues would become increasingly specialized, and therefore more effective in treating these illnesses. In Ontario, the one-stop shopping model of the Community Care Access Centres (CCACs) exemplifies this mentality of specialist services as well as consumer choice. People can be triaged into the program that best met their needs – community case management, special clinics, hospital or community based services et cetera. It was intended to increase accessibility of services and enhance continuity of care. While this is still a work in progress, it seems that a lot of these programs have quite restrictive admission criteria, which essentially is exclusion criteria for the "hard to serve" consumers.

The program I work for is a good example of the "specialty" line of treatment. One of the main problems that I have seen is that the clients who qualify for the service, specifically those who are attempting to get mental health diversion, are defined, processed and treated within the medical model. This is because, as I have outlined above, the medical model of psychiatry holds precedence over more holistic or psychodynamic models. The reductionist approach of psychiatry, which emphasizes personal pathology at the expense of the social context of the problems, is more easily quantified by the people who make funding decisions.

This approach is also better understood by the courts, where there is a need for precision and clarity in the business of dispensing justice, and Crown attorneys are more likely to consider therapeutic measures for an offender if the authoritative figure of the doctor is signing letters, and the diagnosis is sanctioned by medical science.

There is less importance placed on non-medical modes of treatment. Now, the answer is not that one is superior to the other. It is just that in failing to recognize the importance of alternatives, it is ending up costing us more as a society and quite explicitly, in tax payers' dollars, because as aforementioned, the medical model is an expensive one.

The irony is that due to the seemingly quantifiable nature of medical treatments, things are presented in such a way that it makes it look more cost effective on paper than it actually is. I would argue that in spending more time and money upfront on services that consumers have identified as helpful and essential to their well-being – housing, employment, access to dentists – there would be less cost in the long-term.

Unfortunately, I think that the current state of affairs emerges as a result of several influences; however, due to the necessary brevity required of this article, we can only trace so far. If we go back to the Harris government in the 1990s, we could easily discern that the quick pace of globalization, and its infiltration on the corporate world, and in turn the corporate influence on government, had a lot to do with how programs for the social welfare of citizens came to be managed, and their success measured.

In conclusion, this article describes a critical perspective, in economic terms, that attempts to link the larger economic picture of society with specific issues that I have observed in the mental health and justice system. It is not meant to preach doom and gloom or suggest that there is no hope. If anything, it should help to motivate and identify some of the necessary measures to address the "real" needs for consumers that find themselves in this particular section of the arena of mental health services.

Lastly, any organization that exercises power sanctioned by government and legislative authority requires evaluation. Given the breadth of the changes required systemically, ethically and philosophically, there are many potential specific areas for change, daunting as they may be.

[*] Rose-Marie Fraser is a consumer advocate, family member, and works as a social worker and forensic specialist for a general hospital.

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DIGNITY AND RESPECT – BEST PRACTICES IN CLIENT CENTRED MENTAL HEALTH NURSING

Jill-Marie Burke[*]

The Psychiatric Patient Advocate Office's 25th anniversary is an excellent opportunity to celebrate nursing advances in caring for clients with mental health challenges. Two evidence-based best practice guidelines developed by the Registered Nurses' Association of Ontario (RNAO), *Client Centred Care* and *Establishing Therapeutic Relationships*, which are well-regarded by mental health nurses, exemplify a new era and new philosophy in mental health nursing.

Respect, human dignity and acknowledging that clients need to play a key role in making decisions about their care are among the core values of client centred care. The guideline recommends that nurses empower their clients by working in partnership with them. "Clients are the experts about themselves and must be regarded as such," says RNAO President Mary Ferguson-Paré. "We must respect the voice of mental health clients in understanding their situations and what their goals are. And we must listen to their voice with an intent to understand their perspective and incorporate it into how we deliver care."

Registered nurse Pat Nashef, the chair of the RNAO's Mental Health Nursing Interest Group and the manager of two mental health inpatient units and a crisis team at Halton Health Care, says her organization, along with Credit Valley Hospital and Joseph Brant Memorial Hospital, recently implemented a client-centred care initiative called the Tidal Model. This is a recovery model for the promotion of mental health which aims to empower people to lead their own recovery rather than being directed by professionals. It was developed by Professor Phil Barker, Poppy Buchanan-Barker and their colleagues in the United Kingdom. One element of the Tidal Model is an initial assessment which gives the client an opportunity to tell and even write down their own story. They can write answers to questions such as: When did this start? What's worked for you in the past? What do you need? "Whatever their story is, they get to craft it in their own words with their own meaning," explains Nashef. "And the nurse is the apprentice that helps them craft the next step in their recovery. So, it's a really hopeful model that humanizes and brings honour back to every patient."

A therapeutic relationship is defined by the RNAO's guideline as one that is "a purposeful, goal directed relationship that is directed at advancing the best interest and outcome of the client." One way that health-care organizations can enhance the therapeutic relationships between nurses and mental health clients is by utilizing 'primary nursing.' Primary nursing is a method of nursing practice which emphasizes continuity of care by giving one nurse the autonomy and authority to plan, direct, advocate and provide care for an individual throughout the patient's stay and on subsequent admissions to the unit. According to Nashef, primary nursing "looks at the nurse as being the caregiver, but also the care planner. Every nurse owns responsibility for a group of patients and is able to establish a longer, more in-depth, client-focused relationship."

Nashef says the introduction of the Tidal Model and primary nursing have led to very positive outcomes for mental health clients and the nurses who care for them. "We've seen our patients believe in themselves more. We see them feel more honoured and dignified and that their story is profound and meaningful. Nurses tell us that they feel more engaged. They feel more connected and they can drive nursing practice for the best efforts *with* the patient, not *for* the patient. They also feel more satisfaction in their work," she explains.

The current focus on client centred care and therapeutic relationships marks a significant change in the relationship between the professional and the client and family, according to Nashef who has been a mental health nurse for 30 years. "There were always very competent and very brilliant mental health nurses, but the models of care were more patriarchal. We knew best and we did best for the patients. Now it truly is a much more authentic model based on partnership and we're the facilitator rather than the parent."

Now that academic programs in nursing, like the one at York University, are putting the RNAO's guidelines into their curriculum and health-care organizations are incorporating the values into their goals and objectives, people with mental health challenges can be confident that in the near future, the obstacles they face will be understood and respected by all the health-care professionals they encounter.

"I urge all health professionals and the public to treat every person with the utmost dignity and respect," says Doris Grinspun, the RNAO's Executive Director. "In doing so, we will be one step forward in lessening the vulnerability of people who experience mental health challenges."

"We are thankful to the Psychiatric Patient Advocate Office for their tremendous advocacy work and congratulate them on their 25th anniversary," adds Grinspun.

*Jill-Marie Burke is Media Relations Coordinator, Registered Nurses' Association of Ontario.

EDUCATE, EMPOWER, INTERVENE EARLY – TOOLING UP TO IMPROVE MENTAL HEALTH

Karen Liberman* and Donna MacCandlish**

Untreated mood disorders, impacting individuals, their families, friends, co-workers and medical professionals, are debilitating. Timely recognition, in flagging the need for intervention, followed by subsequent action, can significantly reduce personal suffering, enhance individual well-being and reduce health care costs. The Mood Disorders Association of Ontario, in conjunction with leading experts, has developed a website enabling individuals to privately self-assess, become better-informed and source solutions. "Check Up from the Neck Up" (Check Up) is well-poised to enable early intervention, and facilitate partnerships among families and health care professionals to help individuals prevent and recover from the ravages of mental illness.

Focusing on early intervention and illness mitigation

The realities surrounding mental illness (i.e., prevalence, costs, rising significance) are compelling, as is the relevance of early diagnosis and intervention in mitigating and managing conditions. Yet few people check their mental health on a regular basis as they do most aspects of their physical health. With this in mind, we undertook to develop an easy to access, easy to use tool which would screen for potential issues and equip individuals with output that could then be used in consultation with a health care provider. Dr. Anthony Levitt, Chief of Psychiatry at Sunnybrook and Women's College Hospitals, oversaw the development of the screening tools currently featured on Check Up. These move beyond the single depression screens, typically embedded in broader health risk assessment tools. Check Up, in addition to depression, screens for bipolar disorder, general anxiety and panic disorder. The screens have been carefully constructed to gauge propensity, not just current conditions, and employ easy to understand language. Individuals can navigate through the screens in a short time frame (not more than 15 minutes) to generate results.

We encourage individuals to print their screen results so that they can use them in consultation with their respective health care professionals as a starting point for discussions relevant to their mental health. We also encourage users to take the test every six months. In a given month, throughout 2007, roughly 4,000 unique users visited Check Up. Of those, roughly 25% spent a meaningful amount of time on the site and accessed the screening tool. In fact, the screening tool is the most accessed page view on the site (other than the home page).

Lighting the path to help and building treatment partnerships

Educational content on the site is extensive with 14 fact sheets designed to help individuals better understand the various disorders and related conditions. It also helps them understand the various options for support available to them and how to best navigate alternatives. Next to the screening tool, the most frequently accessed page views on the site are the fact sheets on the topics of anxiety, depression and bipolar disorder.

The beauty of Check Up is that it goes beyond simply providing a screening tool and educational content, to actually light the path to sources of help. By simply keying in one's postal code, anywhere across Canada, individuals can determine where they might source local help (e.g., psychologists, counselling, relevant associations and support groups, financial and legal resources) alongside national and provincial resources. It also features a guide for physicians which, again, helps them to know where to refer individuals for support. To date, the guide for physicians has been focused on the Greater Toronto Area, but we have plans to modify this in coming months to become more broad-based.

In comprehensively integrating screening, education and resource links, Check Up offers a "whole greater than the sum of its parts."

Innovating and collaborating to raise awareness

Raising awareness regarding mental illness and battling the associated stigma are priorities for the Mood Disorders Association of Ontario. The better we understand depression, bipolar disorder and various forms of anxiety, the better our chances that people facing these challenges will get the treatment that they need.

With the support of our sponsors and pro bono services of many talented people, we were delighted to launch Check Up in the spring of 2006. We drew attention to the site throughout Toronto, leveraging subway ads, a catchy radio jingle and the video screens at Esso pumps. We were encouraged by the results, witnessing over 115,000 visits to the site within the first seven months. In 2007 we launched a second campaign to create awareness more broadly throughout Ontario, this time in Toronto, Ottawa, Barrie, Hamilton and Windsor. Again, uptake was gratifying. Our objective is to maximize the beneficial impact of Check Up across the country – to see it used often and by many from coast-to-coast. With this in mind, we created a fully translated French site in June 2007 and expanded our underlying resource base to support local communities across the country.

Focusing on the workplace to tackle the challenge

We are now well-poised to add value nationally. However, experience has told us that site awareness is closely linked to media campaigns which, when launched, drive significant traffic to it. In fact, in the months we have launched these campaigns, traffic has increased ten-fold. Unfortunately, such campaigns are prohibitively costly for us. As such, we have focused in recent months on developing innovative strategies to extend the beneficial reach of Check Up.

We know that many Canadians will experience the first symptoms of mood disorders during their prime working years. And we know that over 16 million people are employed by organizations across Canada. The workplace, therefore, is a compelling place to focus our efforts. We are gearing up to equip organizations with a customized version of Check Up to: (1) extend mental health screening, education and support to employees; and (2) provide each participating organization access to aggregate data and benchmarks relevant to their workplace. While employees will have access to a tool with which to privately self-assess and source help as needed, participating employers will be able to gauge the mental health profile within their workplace and extract information that can be used to enhance productivity and enable proactive interventions.

Just as organizations such as the United Way have successfully leveraged corporate campaigns to advance the reach of their services and support, we too see an opportunity to collaborate with like-minded organizations to reach a significant contingent of the Canadian population and encourage routine mental health checks.

Leveraging partnerships for many to benefit

As such, we are seeking to engage with corporate Canada to build and measure best practices for mental health screening, education and resource identification in the workplace. Our collective efforts will be aimed at earlier, more pervasive intervention and, in turn, greater prevention of chronic mental illness and improved rehabilitation for those suffering from it. Over the course of a three year program, we expect to see improved employee health and engagement as well as organizational productivity. We will collaborate with our corporate partners to convert data into information, information into knowledge, knowledge into action an action into outcomes.

We will follow specific information to gauge whether earlier interventions are occurring, including:

- the flow of related traffic to Employee Assistance Program counsellors;
- related drug claims; and
- the review of results with a health care professional. Specifically, we would like to determine how often a person visits the site. If it is other than the first visit, we want to know what action was taken and where screen results have moved directionally.

We hope to witness productivity improvements (reflected in reduced long term disability claims) and improved employee engagement (reflected in elevation of relevant Employee Commitment Index indicators and positive responses to mental wellness awareness surveys internal to participating organizations).

We will value the opportunity, throughout the program, to share knowledge with our partners so as to yield insights regarding best practices. Organizations might implement programs such as:

- semi-annual communications encouraging routine mental health checks and the sharing of results with health care professionals;
- on-line cognitive behavioural therapy; and
- mental health workplace training (employees and managers).

We will, of course, look with great interest to assess outcomes for such organizations. Hopefully we will witness positive correlations among them with earlier interventions, well-being, productivity and engagement.

Suffice to say, we are very excited about our new workplace initiative which has the potential to benefit several stakeholders:

- *Employees* will be equipped with a tool to effectively and privately self-assess, become better-educated and source help;
- *Employers* will be equipped with a tool to gauge aggregate mental health, benchmark trends, improve productivity and earn positive employer profile;
- *Insurance Companies/Employee Assistance Program Providers* will be equipped with a tool to add greater value and reinforce leadership in turning knowledge into action to improve mental health; and
- *Mood Disorders Association of Ontario* will achieve its objective to extend the benefits of Check Up so as to educate, empower and improve mental health.

We remain very excited with the growing activity on our website in the public domain. Take the opportunity to visit us at www.checkupfromtheneckup.ca.

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CONNEXONTARIO: LINKING PEOPLE AND INFORMATION

Brad Davey*

My first job in the mental health field was at one of the Ministry of Health's large provincial psychiatric hospitals. I started working there in 1972 on the Acute/Admitting unit. It was an interesting time to enter the field.

The Vietnam War was drawing to its close but there were still lots of Americans coming to Canada so their sons wouldn't be drafted. A large number of the clinicians at the hospital where I worked were expatriate Americans. They brought some new, and sometimes bizarre, clinical ideas with them. Work was never dull.

In the early 1970s, the trucking industry was not regulated to the extent that it is now. Our hospital was only a few miles from one of the Highway 401 service centres. It was also located about halfway between Toronto and Windsor. Truckers, and the proximity of the service centre, had a direct impact on our caseload at the hospital. Truckers were mostly paid by the mile. The more miles they covered, the more money they made. Their road to fortune was open, so long as they could stay awake. Many truckers running the 401 corridor hit upon the idea of picking up a "buddy" to talk to them and keep awake so that they could get a few more miles logged. We noticed that a significant number of people being admitted to the hospital for the first time had been picked up by police at the service centre. We than realized that truckers were frequently dropping off their "buddies" at the service centre. The outcome, for us, was frequent admissions of folks – who were often disoriented or very ill – from all over the province.

I was very much the "new" guy in the Acute/Admitting unit so I was given the task of trying to find out what I could about the people coming to us for the first time from out of the area. I believe I still have carpal tunnel from the hundreds of numbers I dialed that first summer, trying to locate a social worker in Brockville named Bob, or a nurse in Newmarket named Nancy. The folks we were admitting often had no identification with them and frequently weren't able to give us much in the way of precise information on where they had received services and support "back home." I wondered, at the time, why there wasn't some sort of central contact point for mental health services in Ontario. About 35 years later, I find myself as Executive Director of Connex*Ontario*, an organization which oversees a program providing that very service.

Connex*Ontario* Health Services Information operates three toll-free, provincially-funded information lines: the Drug and Alcohol Registry of Treatment (DART), the Ontario Problem Gambling Helpline (OPGH) and Mental Health Service Information Ontario (MHSIO).

These three information and referral lines are free, confidential, and anonymous. Information and Referral Specialists provide callers with information about thousands of government-funded programs related to drug and/or alcohol use, gambling treatment, and mental health services and supports. Information is available on such things as program and service locations, availability, waiting times, and services available by gender, race and type of substance, to name a few categories. These information lines are available 24 hours a day, 7 days a week, 365 days a year to the general public, substance users, problem gamblers, consumers/survivors, families, friends, health professionals, students and researchers. Callers are provided with assistance in English, French, or via an interpretive service in over 160 other languages. Information and assistance may also be accessed on the internet. Connex*Ontario*'s extensive databases can be accessed by the general public, service providers and clinicians. Our recently-upgraded fibre-optic internet service connection has resulted in a five-fold increase in the speed of our sites.

Connex*Ontario* is a key provider of statistical information on the Mental Health and Addiction sector to the Ministry of Health and Long-Term Care (MOHTLC). Since early 2006, the organization has been engaging with Local Health Integration Networks (LHINs) to assist them in local system mapping and to provide a wide range of data to support the LHIN planning functions. A whole new aspect of Connex*Ontario* is the range of "eServices" online applications that we have developed. These services are currently in use by the LHINs and the MOHLTC and were rolled out to the organizations in our database in September.

It is important to note that Connex*Ontario*, from its earliest days as DART, has a mandate to work closely with the Ontario Health Insurance Plan (OHIP) Out-of-Province unit. Clinicians making application to OHIP for funding to send a client out of the province for treatment must first utilize our directories and cite the results of their search to support their application. According to the Federation of Community Mental Health and Addiction Programs, DART saved the Ministry of Health and Long-Term Care approximately $40 million in out-of-province expenditures in the first two years of its operation.

The MOHLTC recently provided Connex*Ontario* with funding for several new initiatives:

- A pilot project with six problem gambling assessment programs in the province. If callers to the OPGH wish it, our staff is able to electronically book them a first appointment with an assessment service. This "warm line" approach allows us to provide self-assessment tools to callers if they wish to receive them;
- We are the host and builder of the Provincial Human Services and Justice Coordinating Committee's website; and,
- During the course of this year, Connex will be working with stakeholders across the province to build an Eating Disorders Registry of Treatment.

To get a better idea of what our organization has to offer, please log into www.connexontario.ca.

* Brad Davey is the Executive Director of Connex*Ontario*.

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THE ROLE AND CONTRIBUTIONS OF CONSUMER/SURVIVORS IN ONTARIO'S MENTAL HEALTH SYSTEM

Julie Fawm *

The role and contributions of consumer/survivors in the mental health system of Ontario has been wide-spread over the last several years. Consumers have impacted the system by their voices to make the mental health system a better place.

There have been a number of consumer/survivor initiatives across the province that have helped consumer/survivors maintain their role in the community, including, to name a few:

- Ontario Peer Development Initiatives;
- National Network for Mental Health;
- Canadian Mental Health Association;
- Mood Disorders Association of Ontario;
- Recovery Connections;
- Psychiatric Patient Advocate Office; and
- Krasman Centre.

Several of these organizations are well known to service providers, doctors, psychiatrists and consumers working in the mental health system. These organizations help consumer/survivors in many different ways by:

- having caseworkers assisting consumers in their daily lives or to get them back into the workforce;
- sharing information;
- educating and providing expertise and resources;
- advocating for patients rights and systemic hospital issues;
- promoting the mental health and recovery of consumer/survivors; and
- providing a drop-in centre for consumer/survivors in their community to have a place to go to use laundry and kitchen services, where they can meet one another for social activities, peer support, holiday events and workshops.

Recovery is important to consumers/survivors because it gives them hope, choice and empowerment over their journey to get well and to live in their community. It is a personal journey that must be defined by the individual but it helps to have the support of others. Support can come from friends, family members, doctors, agencies and peers. A support system is needed to get the consumer/survivor through the hard times as well as the good times.

Many people in the general population believe people with mental illness are criminals, not worthy of a good life and should be locked up into institutions. This is why people with mental illness feel the stigma and discrimination so strongly in the community. It is hard to recover when the stigma and discrimination is so great.

Consumer/survivors want to be loved and cared for, to contribute to the community, and most of all, to be accepted for who they are as a person and not for their illness. They also want to provide for themselves and their families and again, most of all, to continue to stay well after recovery. During this journey, they also want support and encouragement to do their best in getting themselves to stay well using the resources and services in the community.

Another aspect of consumer/survivors recovery is using peer support workers in the community. These are people with mental illness who seek other consumers to socialize with and exchange ideas and treatments – in other words, to make their lives easier. Workers help consumer/survivors if they are having a bad day and the stress of the illness seems too much for them on that particular day. The peer support worker suggests different coping techniques that they may not have known about.

Many consumer/survivors who are well like to give something back into the community. Some like to volunteer at different agencies and assist staff and consumers. Some like to make their voices known about what needs to be done to improve the mental health system for all consumer/survivors. They sit on committees and Boards of Directors of mental health agencies to make the system better. This takes a lot of hard work because of the stigma and discrimination towards mentally ill persons and the need to pick up on the lingo that the system uses.

I think that all consumers who want to voice their opinion on mental health issues need to know first how the system works in order to get their issue noticed. There are many policies and procedures that must be followed when trying to make change. Consumer/survivors must also realize that funding comes from many different sources and has different rules. For instance, there is first time accord funding where one uses all of the monies at that time; one cannot use it at a later date and time as all of it must be used up.

A new committee from the Mental Health and Addiction Network has formed and it is called the Consumer/Survivor Network. It is comprised of consumer/survivors and consumer/survivor initiative agencies. They have joined together to form a Leadership Committee to advocate for the needs and the voice of individuals and communities served by the Central Local Health Integration Network (LHIN). It will also facilitate communication between the consumer/survivor community and the Central LHIN. At present, it is recruiting consumer/survivors.

I hope you found this article interesting and informative. I am a consumer/survivor myself and unfortunately, when I was going through my journey of recovery, I did not receive the resources or services that are around today. But, I did have an agency that assisted me on my journey and was successful doing so. I am now a stronger and independent person because of the journey. I now want to put back into the community and the mental health and concurrent systems what I got out of the system. I have now been on several committees and attend meetings that I am interested in to improve the system. I recently became a member of the Mental Health and Addiction Network; I have enjoyed learning and getting to know all about the two systems to try to fix them. This has become my passion and purpose in life and I believe it is a big one. I am also doing research and going to school to learn more about the Concurrent Disorders System. On March 28, 2008, I completed the computer online course: Introduction to Concurrent Disorders, offered by the Centre for Addiction and Mental Health. So far, I have learned that it is a very complex system just like the mental health system. As you can see, consumer/survivors can, and do, achieve a successful journey in their recovery and are happy with whom they are. It may take a long time, and one has to be patient because it is not done overnight.

You can see from my story that one can get interested in something and learn what they do not know about it until they do know. A consumer/survivor can do the same thing that I have done to get to know the system and find out what needs to be improved, updated and challenged to make it better for all consumers. It is a lot of work but in the end it is very gratifying. Anybody can do it.

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[*] Julie Fawm, a consumer/survivor in the mental health system, has served as a volunteer in the mental health and addictions system as a committee member. She is passionate in her belief that empowerment will improve both the mental health and addiction and concurrent disorder systems as a whole.

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MY BROTHER HAD SCHIZOPHRENIA – SSSSH... DON'T TELL ANYONE!

Karem Allen[*]

I was thirteen or fourteen years old when my older brother was diagnosed with paranoid schizophrenia. They said it was drug induced but I have a feeling the voices were there first and he turned to drugs to cope.

We were from a small town in the Niagara Region and access to mental health services in 1980 was not the easiest of tasks and from what I understand, it is not much better now.

Just starting high school coupled with living in what was a typical "small town," I was embarrassed to say that I had a brother who was not normal. I saw the troubles my parents were having and especially the problems my brother was experiencing. He was seven years older then I was and he had friends that went on to university and college while he went in another direction. Most of these friends dropped off once word got out.

I think the illness ran in cycles, as each spring an episode occurred that found him needing to be admitted into the hospital. Most times he was willing to go to the hospital but sometimes he was able to say no since he was an adult. If he did not want to go, my mother, although she felt she knew what was best, could not make him.

The police were not involved in our house until a few years later. Fights involving my brother and father sometimes resulted in a hospital admission by way of persuasion because if he were to be admitted against his will a justice of the peace had to be located. It was not easy to gain access to a justice of the peace.

It must be hard to balance the rights of the patient with the family being involved because we have a stake in the health of our family but at what point do we not have a say?

Was my safety not important as I also lived in the same house as my brother?

My brother either worked on the ships or lived at our house. When the illness progressed more, he was let go from his job. One time he stole my mother's car, left the car in Buffalo and took a bus to South Carolina. He ended up going to a hospital there and a caring doctor called my parents who set off at 2 am from our home in the Niagara Region to retrieve him. This was yet another strain on the family as things were not perfect already. The family was, to say the least, dysfunctional but these were the days when you did not share this type of information. My brother's illness was not the cause of our family problems but I am sure the way he perceived things affected his treatment. I had issues with him but in time, as I got older, I cared less about what my friends thought and it was more a matter of just not understanding what he was going through.

My brother developed a fascination with knives, ranging from pen knifes all the way to machetes. He started reading the bible for hours on end, standing in the hallway. His face was twitching sometimes from the side effects of the medication.

February 20, 1983 in the evening the police were at my house when I arrived home from an evening out with a friend. This was not the first time they had been at the house but this time was different – my brother had threatened my father with a machete. My mother wanted him to be taken to the hospital, as it was obvious he needed care. But, the police left and my brother was still in the house. Things had settled down a bit but, of course, my father was shaken up. We had no idea what was going to happen the next morning.

My mother went to the police station in the morning to request the justice of the peace sign an order so my brother would be admitted to the hospital for treatment. While my mother sat in the police station, I was at home on a holiday from school and was getting ready to go out. I heard a loud crash in the kitchen and ran out to see what happened. My brother was stabbing my father and there was nothing I could do. I fled the house and ran to the neighbours and the police were called. When I arrived at the police station, my mother had not been informed about what had happened. They had moved her to another room when the call came over the radio. She was confused when she saw me and wondered why I was at the station as I was not the most perfect child myself at the time and she thought I was in trouble for something. My father was dead.

This was the beginning of another phase of dealing with my brother's issues. I was seventeen years old at the time. He was found not guilty by reason of insanity, as it was called then, after a trial in Welland. I was supposed to testify but the Crown Attorney, at the last minute, decided that I did not need to testify. By the time I finished high school, he was in maximum security at what is now called Penetanguishene Mental Health Centre.

Next, there were yearly reviews and assessments. My brother was moved to St. Thomas then to Hamilton as an out-patient. After some experimentation with medication in 1987, he was again experiencing issues so he was sent back to St. Thomas. I was in Port Stanley at the time and I cannot explain it but when I drove past the hospital, I had a feeling he was there. I received the message about his transfer once I arrived at home.

Fast forward to 1992 – my brother was an outpatient in Hamilton, married a woman and was a step-father. He walked me down the aisle for my wedding even. Things were going well or so we thought. On Labour Day weekend in 1993, ten years after my father's death, my brother took his own life as he found the side effects of his medication more then he could bare and he was dealing with thoughts that he could not control. He feared a repeat incident based on his note.

Access to mental health professionals is an issue whether you are under the jurisdiction of the courts or a private citizen. We need to ensure people can get the help they need when they need it. Mental health is no different then cancer but the stigma remains. To this day, I am hesitant to talk about my family's past issues. Although depression seems to have become more fashionable and accepted, schizophrenia is still not as popular. Our entire family needed care and if it were not for the support of my friends and my mother, I may have taken a different path myself; but I coped. My mother coped, but she lost a husband and son. Part of my brother's personal demons came from the previous loss of our brother to a car accident in 1972, and the fact our family never really recovered from that.

I want the rights of patients to be advocated for, but I also want to see families cared for and supported in their efforts to care for loved ones that have mental health issues. Medications are better now but when behaviour begins to deteriorate, family members usually see this first and they need to be listened to.

I cannot change what happened 25 years ago, but has the system changed?

[*] Karem Allen lives in Durham Region with her Family.

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REMEMBERING NICHOLAS

Written and shared by:
Penny Knapp (Mom),[*] Marsha Knapp (Sister)[**] and Melanie McLeod (Sister)[†]

Oh how I long to hug my son, hear him say: "I love you. Get a life, Pen." There is such a feeling of emptiness within. I have moments of emotional pain where tears will fall without any self-control. Grieving – I am only grieving, please don't let me grieve alone. Stay with me; listen to me as I tell you my pain.

This is the time to surround myself with pictures of my son, watch a video clip of him and recall the memories in his baby book. I go up to his room and immerse myself in his belongings and the scent of his body in his clothing before it fades. I look at each picture and remember the time that relates to the photo. I remember when he went to his friend's house for the first time. There was his birthday party we surprised him with, the whole class yelling "surprise." I made a birthday cake in the shape of a front-end loader.

Oh, son, I wish you well and no more pain. I know you never meant to hurt your father and I, or your sisters. I just never knew you were hurting so much. I will always remember you as the considerate, thoughtful, full of life, energetic, living on the edge son, brother and friend. I will not grieve sadness. I will only allow positive grieving for you because you knew not what you were doing. I will support you, love you and respect your decisions. I realize I have no influence over what happens to any one of my young adult children when they leave the house.

Nicholas, my son, when I feel sad I tell myself: "you have taken your life, not my life." I still have so much living to do. Every morning I wake up remembering what I am grateful and thankful for, and each time, it is the fact I had 20 years with you. I carried you for nine months and you were born to me. I had the pleasure of being your mother. We are your family. Thank you for this. I am grateful for all the times you made me proud to be your mom. Nicholas, I will remember you most for your thoughtfulness and the memories you have given me. The times we laughed and the times we cried and the times we disagreed because we were being unfair with the rules of dating, dances or not being able to watch "The Simpsons." Remember the time you had to do 40 hours of community service? You volunteered to collect for the Kidney foundation. The times you delivered the St. Thomas newspaper after school and I'd say: "don't talk to strangers, stay out of their houses." You would reply: "it's all good, mom, don't worry."

When I'm sad, don't leave me alone, don't walk away. I am only grieving. There are no magic words to say. It's okay when you don't know what to say.

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My younger brother, Nicholas, died by suicide at the age of 20. A huge weight lifted when I took out the word "committed." It is such a loaded negative word. "Nicholas died by suicide" is a more accurate way of describing what happened.

It was not the Nicholas I knew that took his own life; it was a sad, hopeless Nicholas that must have been hurting so much that he thought death was his only relief. I am very saddened that at that moment I feel Nick was short sighted and could not hear his future calling. Coping with Nicholas' loss is a continuous rollercoaster of emotions. I go from being sad to happy to taking his death personally to asking why and becoming overwhelmed with guilt. I have learned the importance of going through all the stages of grief (sometimes more than once) without judgment. Every day I remind myself to be gentle with myself. I have a strong need to feel connected with my family; not only is it important to grieve at my own pace alone, it's also important to grieve openly with my family. The first few weeks after Nick's death my family and I were in a cocoon – a safe haven – together. The strength I got from this helped me to slowly go back into the world accepting the fact this has changed me. I'm so blessed to have a strong, supportive family by my side.

Coping with Nick's loss just isn't enough for me. I have to do something in the name of Nicholas and that is to talk openly about how suicide has affected me, my family and my hometown. I am amazed at how many people have been touched by suicide. I'm still astonished with the statistical data surrounding it and I'm saddened so many young people – especially boys – attempt suicide. I have a strong passion to make this world feel safer to young people. I need to find ways to bring hope to kids and to let them know that each and every one of them is a valuable, indispensable human being that is an integral element to today's society. I began just by feeling this need for change, then by talking about it and then by reaching out for help.

I'm so thankful to everyone who reached towards me. I see a bright future and I know that Nicholas' death was not in vain. I may have physically lost my brother, but I have found him within me. I have gained perspectives, support and a vision – a vision of how our youth need to be regarded with much more respect and dignity. I hope this also brings comfort to my mourning family and hometown community. I can tell a community's sustainability by how their youth – their futures of tomorrow – are taken care of, regarded and included. I hope the initiatives our family and community are taking toward youth programming will help all young people see and feel their own value.

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The death of my brother isn't some event in my life I have to get over. You grieve and cope with the death of a loved one and then it becomes a part of who you are. I am a young woman who lost her brother from suicide. I will never forget that and I can only move on once I realize this event in my life and in my family's life has now become a part of who we are. But it doesn't make it easier to forget about. You need to keep on living, but not talking about it won't help you move on. I live every day with a new part of me that has changed because of this experience of losing my brother to suicide; it has made me who I am today, much stronger. I never want to forget him. My whole family wants to do whatever we can to remember him and the times we had together as a family.

We have discovered that golf is something a lot of my family members have in common. It's relaxing, outdoors, on an amazing landscape and a part of the life we had with my brother. So, what better way to remember him then to golf in his memory? My entire family, including extended aunts, uncles, cousins and grandparents ran our 1st Annual Memorial Golf Tournament for my brother. We raised over $20,000, we spoke out, spread the word on suicide and educated families and parents about their kids and about this secret disease.

The silence needs to be broken. SAY IT OUT LOUD! Stop whispering about it, make it known that we are not ashamed. We need to share our experiences and successes so kids feel less alone and helpless. But we can't stop there. Because we are from a small town, resources for youth are scarce. We can talk about all the skills you need as a parent or child, but where can you go to get them? During the course of the golf tournament, we made numerous contacts with people who have struggled like us and made a difference in their own towns. We are now applying their lessons, skills and experience to our own town. Currently we have a small youth drop in centre, which is now expanding. We need to help this resource grow not only for the benefit of our community but most of all for the kids. This centre is intended to be a home where all youth can go to express themselves, be a part of something bigger – something important to them – and give them a purpose to keep on living their fullest potential. This will also give them the pride and respect they deserve, plus the responsibility and confidence to want to make a difference in their own lives. If we can change the mind of one more person who might feel alone, and helpless, it will mean the world to me and my family. I currently work at this youth centre, which we call "Centre Ice" and will only try harder to touch the lives of the youth in this community..

Thank you to all our family and friends for your continued support and motivation. We love you. Thank you to our new found friendships for your educational inspiration and guidance. You have all helped my family and our community to always remember Nicholas.

[*] Penny Knapp is honoured to have been the chosen one to have given birth to Nicholas. She currently works in administration in London, Ontario.

[**] Marsha Knapp is Nicholas' oldest sister. She currently works in the Film Entertainment industry as a Production Coordinator for IMAX Corporation in Mississauga, Ontario.

[†] Melanie McLeod is the middle child and four years older then Nicholas. She currently lives in Dutton Ontario, and is a Child and Youth Worker at the West Elgin Community Health Centre.

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MENTAL HEALTH SERVICES FOR ABORIGINAL WOMEN: DISPARITIES OF CARE

Angie Conte*

Disparities of care exist in mental health services for Aboriginal women that adversely affect their health and well-being. This results from problems with access, the intersection of multiple oppressive statuses and social conditions of this group, and the separation of medical models of care from traditional native healing practices. An awareness of the determinants affecting Aboriginal women's mental health is required in the forefront of service provision to address their needs. This discussion is highlighted by my experiences as a white Residential Counsellor in a Native women's shelter, as I learned from women within the system about their views on mental health issues and the healing process.

Problems with Access

In general, women access mental health services and receive treatment more often than men.[1] Native women have more difficulty accessing services due to differences in the rural versus urban experience, inappropriate or non-existent services, and jurisdictional issues.

In Canada, an increased migration of young adults from mid-Western and Northern reserves, coupled with difficulties integrating into the urban context, has resulted in higher rates of homelessness, where Aboriginals are already overrepresented in this population.[2,3,4] Access to adequate, safe housing is a key factor in attaining and maintaining mental health.[5] Moreover, homelessness is recognized as a root cause of mental health problems for Aboriginal people.[6] Many reserves lack adequate housing and special housing initiatives, such as services for mental health needs, or safe housing for women and children. Consequently, these groups filter into urban centers to access much needed services. Relocation and homelessness however, impede access to service, put individuals at greater risk of abuse, and exacerbate mental health problems through reduced resources and capacity.

Another barrier to access is non-existent or inappropriate services. Finding services for Aboriginal women with special or multiple needs is often difficult as there are few supports available.[7] For example, admission criteria at the Native women's shelter preclude the use of substances though many women have co-occurring substance use and mental health problems. A problem for mental health care is the separation of alcohol and drug addictions, where depression or anxiety disorders may result in use.[8] In addition, an observed practice at the shelter has been to not accept "difficult" or "high needs" women with more severe mental health problems. Most workers feel there is a lack of training, ability and resources to deal with this group. More generally problematic within the Aboriginal context is a "lack of education, training, and support for mental health care providers on the front line."[9]

Culturally mandated services can also be in tension with other mandates of an organization. For example, this Native's women's shelter is both a Violence Against Women shelter and Native women's residence, open to both native and non-native women. Some native residents have expressed a greater sense of support and community when the residence has native only clients. Similarly, cultural "clashes" between residents and staff and between both groups with one another present an ongoing challenge.

Institutionalization can also reduce the desire and comfort level of individuals to access services. In a residential setting, there are restrictions around eating and sleeping times, and the posting of "house rules." Residents are rarely involved in these decision-making processes, or the formulation of policies and practices. This undermines personal agency and the relational aspects of native culture that include mutual sharing, respect and responsibility. The abuses suffered by many Aboriginal women in institutional settings such as the residential schools, has also engendered a distrust of government agencies and services.[10]

Finally, jurisdictional issues arise across the mandates, programming and funding of Aboriginal services. Currently, there is no core Aboriginal mental health program federally or provincially, and regional boundaries and differences in reserve and urban service provision are problematic for allocating and accessing appropriate service.[11]

Intersecting Oppressions

Notions of health are now more widely inclusive of the emotional, social, physical and cultural aspects that affect well-being, and may be placed alongside determinants of health which include political, economic and biological factors.[12] The intersection of multiple oppressive statuses and social conditions such as gender, ethnicity, poverty and violence, all impact Aboriginal women's mental health status.

Aboriginal women are dually marginalized as both women and Native persons. The role of gender affects women through the pathologizing and over-medication of their health concerns in the mental health care system.[13] Similarly, Aboriginal women tend to be portrayed as victims in mainstream policy and research. Experiences of racism and cultural insensitivity in the system also discourage future access.[14]

Internalized racism occurs where negative messages are held and directed inward and negate an individual's sense of their right or perceived benefit of seeking assistance. This is extremely harmful to the mental health of Aboriginal peoples who are also conflicted by identity issues. As the Clinical Head of Aboriginal Services at the Centre for Addiction and Mental Health explains, most Aboriginal children grew up "white" or in white homes when removed from their families, creating a crisis between feeling white and looking Native.[15] Negative mainstream stereotypes about Aboriginals and racialized violence on the streets, also contribute to women's experiences of abuse and poor mental health. One woman at the shelter had been kicked and spit on by pedestrians shouting racialized comments as she sat on the street with friends.

Research shows Aboriginal men and women have a "health profile characterized as similar to those in the developing world."[16] Women are also poorer than men, especially elderly, aboriginal and single mothers;[17] and Aboriginals are more likely to be poorer than other Canadians.[18] Similarly, native persons are disproportionately represented within problem groups such as the incarcerated, homeless, substance users, and those experiencing family violence.

While women are at a greater risk of interpersonal violence, Aboriginal women are "more likely to inhabit an environment where substance use and violence are widespread."[19] Health related consequences of violence include mental health problems, substance abuse, and self- harm. It has been found that substance use and mental health problems co-occur among women survivors of violence, abuse and trauma.[20] Such differing social experiences affect mental health and should not be separated from aspects of care in service provision, but addressed alongside the treatment of symptoms. Mental health services should incorporate treatment and support for women with present and past experiences of physical and sexual violence.[21]

Medical Models and Native Healing

There currently exists a separation of Western medical models of care from traditional native healing practices based on holistic notions of health. White service provision can also create a divide in delivery. For example, some white educated staff, (those who hold accredited degrees) may possess theoretical knowledge, but have little or no experience in the Aboriginal community whereas their Aboriginal counterparts possess cultural knowledge and traditional healing methods not obtained through formal education. The perception of these two approaches as incompatible is misguided, creates disparities of care, and puts Aboriginal women at risk of not having their mental health needs met. Rather, both approaches should be viewed as co-existing options for mental health care, and remain open to those wishing to pursue them.

Historically, the traditions, values, and belief systems of First Nations and Aboriginals are poorly understood, not respected, or even considered by service providers, leading to devaluing and marginalization.[22] One woman at the shelter recounts how she stopped taking her medication with no medical support when her psychiatrist refused to continue care if she insisted on incorporating native healing practices as part of treatment. This "all or nothing" response led to her emotional, mental, and physical deterioration over two years, as she was forced to leave her job and turned to substance use to cope with symptoms. Eventually, this woman was able to combine alternate forms of care after finding a practitioner who agreed to supervise both strategies as long as she was trying "something."

This story exemplifies how a Western understanding of health and illness is "strongly influenced by psychiatry with its attachment to biomedical traditions, individualistic approaches to treatment and history of cultural blindness."[23] Interestingly, Aboriginals may be more concerned with mental health issues that are the result of environmental factors, rather than biological, medically defined disorders. This belief may be due in part to their connection with the natural environment, but also concern for community. Problems such as homelessness, violence and discrimination, which impact mental health, are viewed as a threat to the community as a whole, but also, as issues the community can affect and address. Therefore, there is a need to incorporate an investigation of the indicators of health and native concerns alongside mental health illness with a delivery system that accommodates socially embedded mental health needs.[24]

An Aboriginal view of mental health is a holistic perspective, where problems are "a reflection of imbalance or disharmony in the circle of physical, emotional, intellectual and spiritual dimensions of the self… and are closely tied to both the physical and social environments."[25] An approach to meeting Aboriginal women's mental health care needs necessitates broadening service provision to include holistic, multidisciplinary and community responses.

The use of empowerment models for example, could support self-sufficient, self-determining elements key to Aboriginal individuals. Many Aboriginal women at the shelter currently taking medication still express a real fear of losing control and independence when the system "takes over." Similarly, the vital role of Aboriginal women as caregivers, leaders, and nurturers needs to be recognized and incorporated into Western approaches to health care and service provision.[26] When practitioners make room for alternate forms of treatment such as traditional native healing practices, they support personal agency which promotes the betterment of mental health. Some women at the shelter reported the significance and effectiveness of combining both traditional and Western medicine and practices. For example, many women use traditional medicines such as sage and tobacco as a restorative practice along with prescribed medications.

Community level intervention, such as the use of elders, family members and healing circles, could also be utilized in addition to community treatment teams. The use of elders, similar to that of a health care professional, is to partner younger women with respected "experts" of the community to provide support and guidance through sharing knowledge. Family and community is also a "core institution of Aboriginal society."[27] Current examples in mental health care involving family members as sources of support are found in community treatment plans, implemented when some patients are discharged from hospital. Similarly, Assertive Community Treatment Teams are often used to support treatment regimens. They provide consumer directed, flexible, team approaches, making them distinct from other models and fitting in reserve communities. In Native communities, healing circles are used to encourage spirituality, renew community ties, and enhance self-esteem and empowerment.[28]

Ultimately, the mental health care needs of Aboriginal women need to be both balanced and contextualized within their communities, and in consideration of the determinants affecting their health. Western medical models of care and traditional native healing practices have remained separate entities. While distinct, both can be used to formulate improved options for care when the door is opened for mutual respect, understanding and consideration of each perspective.

[*] Angie Conte, BSW, is a Rights Adviser with the Psychiatric Patient Advocate Office, Toronto and a Residential Counsellor at Anduhyaun Inc. Native women's shelter (Toronto). She would like to acknowledge the many women of the Native community who inspired this piece.

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[15] *Supra* note 4.

[16] *Supra* note 2:12.

[17] *Supra* note 1:3.

[18] *Supra* note 2:15.

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[20] *Supra* note 13:4.

[21] *Supra* note 1:10.

[22] *Supra* note 6:3.

[23] *Ibid.* at 8.

[24] *Supra* note 13:6-7.

[25] *Supra* note 6:24.

[26] *Supra* note 2:18.

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A COLLABORATIVE APPROACH TO CARE FOR PEOPLE WITH DUAL DISORDERS

Janet Sillman*

Background Information

Lakehead Psychiatric Hospital (LPH), formerly Ontario Hospital-Port Arthur, opened in 1954 with planned capacity for 1200 inpatients. For more than five decades, services were provided to a variety of target populations, including adults and children with serious mental illnesses, acquired brain injuries, intellectual disabilities, substance abuse issues and dementia. The Northwest Regional Centre operated within LPH, but was funded by the Ministry of Community and Social Services (MCSS); the Centre provided inpatient and outpatient programs for people with intellectual disabilities.

In 1986, 170 psychiatric hospital beds at LPH were dedicated to the provision of care for adults and children with intellectual disabilities. However, with the goal to repatriate this target group to their home communities, group homes were established throughout the region and the clients were discharged from inpatient care. The transition process took almost ten years and, in 1996, the Northwest Regional Centre formally closed.

Funding and policy development were provided by MCSS to support the client transition process and service sustainability. A number of community-based agencies were expanded or established to provide more comprehensive services and support for clients with intellectual disabilities and their families/caregivers.

Many people with intellectual disabilities have lived successfully in their home communities subsequent to their discharge from the hospital. However, community agency and hospital resources were insufficient to meet the needs of people with complex intellectual, behavioural and/or psychiatric issues. Representatives and care providers from the developmental services and mental health sectors indicated they did not have the training, expertise or the resources to provide the most appropriate care for this target group. At times, clients bounced back and forth between providers. Solutions were not forthcoming; clients and their families struggled.

Assessment of Need

In 1999, the Comprehensive Assessment Project (CAP)[1] was completed for all inpatients of LPH. This province-wide initiative included an evaluation of the current and projected needs, including accommodation and community support requirements.

In 2003, the Centre for Addiction and Mental Health (CAMH) researchers carried out a more comprehensive review of the CAP database, with a focus on people with a dual diagnosis.[2] They defined dual diagnosis as a *"co-occurrence of a mental health problem and an intellectual disability."*

The initial findings, based on provincial data, were as follows:

- 1 in 8 provincial psychiatric patients has a dual diagnosis;
- 80% of those patients were served in generic programs;
- 37% of inpatients with a dual diagnosis had been hospitalized for more than 5 years; and
- the target group had more severe symptoms, fewer resources and required a higher level of care than other patients.

In 2004, Y. Lunsky and J. Puddicombe, CAMH, met with stakeholders throughout the province to share the CAMH research results and find out about key issues facing providers, family members and referents. These roundtable discussions[3] revealed the following issues:

- insufficient case management and residential support services;
- lengthy wait times to access supportive housing;
- lack of specialized services, resulting in "ping-pong" client care between service sectors;
- insufficient specialized training for staff;
- insufficient human resources; and
- frustrated families have concerns about future care options.

The researchers/facilitators recommended the following:

- a more comprehensive range of services within a full continuum of care;
- a reduction in the barriers to access care;
- a commitment to the goal to support community living, whenever possible;
- the establishment of crisis services in the community and a reduction in the reliance on hospital emergency departments; and
- a focus on early recognition of symptom escalation and the provision of support and treatment in the client's natural setting wherever possible.

Regional Commitment and Planning

In 2005, Y. Lunsky and J. Puddicombe, met a second time with Northwestern Ontario representatives from: agencies that provide clinical and support services for people with a dual diagnosis; MCSS; Ministry of Health and Long-Term Care (MOHLTC); and Ministry of Child and

Youth Services. They provided an overview of the CAMH findings and challenged the participants to work together collaboratively to bridge gaps in service delivery using existing resources.[4] The participants were committed to build strategies that would improve the quality of life for individuals with a dual diagnosis.

The Northwestern Ontario Dual Diagnosis Working Group held its first meeting in the spring of 2005 and continued to meet quarterly for two years. The members supported the following vision:

> Persons with developmental disabilities and their families/supports will have timely and equitable access to a continuum of health and mental health supports and services, within and across sectors, that are integrated, coordinated and least restrictive. Services will be client-directed and personal autonomy will be fully supported. Optimal levels of successful living will be the goal.[5]

The primary purpose of this group was to develop an integrated and coordinated system of care and service delivery that meets the unique needs of individuals with dual disorders using the most appropriate level of resources, including community and hospital care providers.

The working group identified a number of real or perceived barriers to system change, including:

- service doors closed due to dual disorder diagnosis;
- service doors closed due to lack of a diagnosis;
- lack of integrated planning, funding and policy development within and between MCSS and MOHLTC;
- insufficient staff and recruitment/retention issues;
- lack of specialized knowledge, skills and experience;
- geographic and funding issues related to training;
- philosophical differences in principles of care between the two sectors; and
- silo funding.

The members also developed an inventory of current services and service system gaps, identified components of the system that could be better coordinated and determined strategies to achieve their adopted vision of care and service. They agreed to meet, as required, in the future to support initiatives to build system capacity.

External Forces and Supporting Initiatives

The plans of the MOHLTC to significantly reduce psychiatric hospital beds throughout Ontario generated region-wide concern about future care for people with a dual diagnosis. St. Joseph's Care Group[6] planned to establish supportive housing to meet the needs of long-stay inpatients who did not require ongoing hospital care and who could live safely in the community with support. Concomitantly, the MCSS was developing plans to transform community-based developmental services.

Reduction in Psychiatric Hospital Beds

In 1996, the Health Services Restructuring Commission directed St. Joseph's Care Group to assume governance and management of LPH, to build a new 38-bed mental health rehabilitation facility on an alternate site and to close LPH. This capital project is currently underway and the new facility will be ready for occupancy in 2011.

The Northwestern Ontario Dual Disorder Working Group acknowledged that the closure of LPH and the reduction in psychiatric hospital beds would compromise the availability of inpatient resources for the dual disorder population. The group agreed to support and advocate for initiatives to establish appropriate community-based services to meet the needs of people with dual disorders, including the provision of community-based specialized clinical services and supportive housing.

The Board of Directors and Leadership Team of St. Joseph's Care Group were fully committed to establishing appropriate supportive housing for inpatients of LPH. The Care Group operated four high and medium support homes and alternate residences[7] (with a total of more than 80 spaces); however, people with complex dual disorders did not meet the criteria for admission into these homes.

Ministry of Community and Social Services Transformation Plans

The North Community Network of Specialized Care, established in 2006, is one of four networks across the province with a mission to support adults with a dual diagnosis. It was clearly identified that partnership arrangements between the MCSS and MOHLTC funded agencies and collaboration amongst all stakeholders were vital ingredients for successful service integration.

MCSS provided operating funds, through "lead agencies" in the province, to establish specialized services for people with dual disorders. Algonquin Child and Family Services is the Lead Agency for Northern Ontario and, in this role, encouraged community groups to work together to propose new and unique models of care.

A group of developmental service and mental health care providers developed a joint proposal to provide a coordinated approach to supporting individuals with a developmental disability and a mental health issue and/or challenging behaviour. The proposal focused on enhancing existing resources, building system capacity and establishing specialized accommodation for short-term, intensive assessment, stabilization and treatment for people whose needs could not be met in their normal home/residential setting.

The model of care was approved and funded by MCSS. The three major components are described below:

1. A referral/intake component consisting of an initial assessment completed by the Community Specialized Service Team Coordinator.
2. A residential support component consisting of well-trained front line staff who are able to deal with a person encountering serious behavioural challenges and/or a mental health issue. This support can be provided either within the individual's existing residence or within an identified specialized support residence outside of their principle residence. The specialized support residence will be a safe, therapeutic and habilitative environment.
3. A local Community Specialized Service Team component that is responsive to urgent requests from individuals in the community.

Specialized High Support Home Established

In partnership with a not-for-profit property management company, St. Joseph's Care Group opened a new high support home in Thunder Bay in January 2008. The five bedroom bi-level home was renovated to accommodate a one-bed apartment on the ground floor.

The five tenants, with a primary diagnosis of a developmental delay and a mental illness, were previous inpatients of LPH who did not meet the criteria for tenancy in the other high support residences. The individuals had been long stay inpatients, with a range of 365 to 3409 hospital days since first admission. The five tenants, one male and four females, range in age from 28 to 53 years.

The specialized unit was designed specifically as a resource for the residential support component of the North Network model of care. The renovation project and ongoing operating costs of this unit are funded by MCSS.

Principles of psychosocial rehabilitation and recovery are key elements of the care provided in this home. Tenants have the opportunity to live independently with appropriate supports and care provided by a team of care providers with specialized knowledge and skills to meet the needs of this group of people with very complex needs.

From Vision to Reality

It has been almost three years since the first meeting of people representing agencies that provide services for people with developmental and behavioural and/or mental health issues. Throughout the planning and implementation processes, each participant demonstrated a commitment to serve, provided leadership within their organizations and the system and demonstrated a willingness to collaborate, partner and share resources. The special needs of people with a dual disorder and their family support systems were clearly the focus of all discussions and the driving force behind all decisions.

The Ministry of Community and Social Services and the Northwest Local Health Integration Network recognized the importance of collaboration regardless of funding source and were fully committed to work together. The establishment of a system of care and service that "worked" was clearly their priority.

Next Steps

This initiative is just in its infancy. Programs are being developed and established, evaluations are underway and strong working relationships between and within organizations are emerging. The project has been exciting for everyone involved.

We cannot, however, lose sight of the fact that more services are required. More high support housing options, increased staff resources and additional resources for training, education and mentoring are needed throughout the region. The members of the working group have the experience and the desire to develop new initiatives to address these needs.

This quote by Margaret Mead truly describes the community and regional collaboration that took place in Northwestern Ontario:

> *A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has.*

*Janet Sillman is Vice President of Mental Health and Addiction Services for St. Joseph's Care Group in Thunder Bay.

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1 This province-wide initiative was funded by the Ministry of Health and Long-Term Care and carried out by the Centre of Addiction and Mental Health, 1999-2003.

2 Lunsky Y, Bradley E, Durbin J, et al: The Clinical Profile and Service Needs of Hospitalized Adults with Mental Retardation and a Psychiatric Diagnosis. Psychiatric Services 57 (1): 77-83, 2006.

3 Y. Lunsky and J. Puddicombe. Dual Diagnosis in Provincial Psychiatric Hospitals. Advisory Group Presentation to Service Providers in Northwestern Ontario, 2004.

4 Y. Lunsky and J. Puddicombe. Dual Diagnosis in Ontario's Psychiatric Hospitals. A Roundtable Discussion regarding Service Needs in Northwestern Ontario, 2005.

5 Inter-ministerial Dual Diagnosis Guidelines.

6 St. Joseph's Care Group is a multi-site health care corporation that provides inpatient, residential and outpatient services in Complex Care, Physical Rehabilitation, Long Term Care, Mental Health and Addiction Treatment.

7 High support homes provide onsite 24 hour clinical care; medium support homes provide 24 hour on-site support services with regular visits by mental health clinicians; alternate residences are within the Homes for Special Care program of the Ministry of Health and Long-Term Care

HISTORICAL ISSUES, PRESENT DAY DEVELOPMENTS AND STEPS MOVING FORWARD IN SERVICES FOR INDIVIDUALS WITH A DUAL DIAGNOSIS - ONE PERSON'S PERSPECTIVE

Arthur W. Mathews *

In recent years, treatment services for individuals identified as having mental health issues have taken great strides. The stigma related to mental health problems is decreasing and the community is developing more services and supports for individuals who may have some mental health challenges. These positive developments have been the direct result of a significant number of changes within society, including shifts in provincial policy related to mental health reform and watershed position papers, such as *Making It Happen*, and technological developments, such as advances in medication and psycho-educational treatment regimes. In addition, legal reforms such as the development of community treatment orders, the implementation of new consent and capacity standards and a renewed recognition of the rights of the individual to receive, participate in and direct their treatment, have also contributed to these positive shifts.

Similarly, positive developments have been achieved in the programs and services in place for individuals who are identified as having a developmental handicap (also known as dual diagnosis). Philosophical shifts such as the community living movement, policy reform such as those promoted by *Making Services Work for People*, and a better understanding of how to support individuals as individuals have all contributed to these steps forward.

In contrast to the above, people who have coexisting mental health issues and an identified developmental handicap (anywhere from 24,000 to 36,000 people in the province of Ontario)[1] continue to experience significant challenges in receiving the required treatment and ongoing support they require within the community environment.

In examining this field of practice, one sees that over the last 25 years, issues related to community capacity, the "technology" of treatment/support and political mandate, have all served to place persons with a dual diagnosis last in terms of service priority and effectiveness.

Historical Issues

Treatment and Support Services

While the community living movement and mental health reform have done admirable work bringing people out of institutions, the same cannot be said for individuals who have a dual diagnosis. Deinstitutionalization traditionally focused on individuals with the least challenging sets of needs as the community and support systems of the time were unable to support people with very complex and challenging needs. As a result, a move to the community for folks who had been identified as having a dual diagnosis did not happen in step with these other important initiatives.

Challenges associated with the ability of professionals within the health care and social service system to diagnose and treat people are another such issue. The combination of mental health issues (often manifested as severe behavioural concerns) and an identified developmental handicap has meant that the ability to appropriately understand the individual's needs and to establish a related treatment protocol has been an ongoing challenge. Indeed, since there are many different types of mental illness (each with their own manifestations) and several degrees of developmental handicap, many of the usual diagnostic techniques, standardized assessments and clinical indicators do not apply to this population. As a result, the process of defining the problems and the related solutions/treatment is significantly more time consuming, labour intensive, and directly dependent upon the observational powers of the clinician/team and their ability to discern the various components of an individual's presentation within the clinical context. This reality is made even more challenging when one considers that, because of the compromised neurological systems of these individuals, the impacts of psychotropic medications can often vary from the usual and expected, thereby making treatment a far more challenging endeavour.

Policy and Mandate

To date, though there is a set of guidelines that addresses the need for Ministry of Community and Social Services and Ministry of Health and Long-Term Care funded agencies to cooperate in the delivery of services to individuals who are identified as having a dual diagnosis, there is no "teeth" behind it, nor does it mandate that the acute treatment needs and ongoing community living support requirements of individuals who are identified as having a dual diagnosis must be addressed. This gap translates into a lack of funding for community-based treatment and support for these individuals and, in addition, allows a situation where there's often no agency accountability for services and supports for these individuals. Indeed, one of the traps that have been a challenge for these individuals and their families is the fact that some associations for community living will not support these individuals because their mental health needs is not within their agency mandate and some mental health treatment programs will not support these individuals because of their perceived developmental handicap. Instead, in these instances, each refers to the other when presented with an individual who may have a dual diagnosis – with the end result that these individuals and their families do not receive services.

Present Day Development

The concerns noted above remain to this day as evidenced by a 2005 study conducted by Whitby Mental Health Centre (on behalf of the Ministry of Children and Youth Services) in the Region of Durham. [2] This work found that the greatest needs for youth with a dual diagnosis (and their families) included: specialized treatment and relief services; improved crisis intervention; enhanced follow-up to assist the individual to stay in the community; and a glaring need for dedicated supports for the families in order to assist in maintaining the integrity of the person's support network. Having said that, it is important to note that there has been some significant progress in the last three years since this study at the individual, local and provincial levels in regards to supporting individuals who are identified as having a dual diagnosis.

Treatment and Support Services

Much more research specifically related to the challenges of supporting individuals identified as having a dual diagnosis has taken place. Organizations such as The National Association for the Dually Diagnosed (NADD) have taken a leadership role in assisting with the development of the best assessment and treatment regimes available for this population.

Specialized post-secondary educational programs related to topics such as behavioural intervention have served to assist in a creation of a supportive workforce that has a far better understanding of how to interact with and support people of different needs.

People working in the field are also developing a far better understanding of the impacts of the environment on individuals with very complex needs. Consequently, they have been able to reflect such understanding in the development of specialized living environments for these individuals when required.

Acute care, tertiary care and community based service sectors are developing better understandings as to how to best support individuals who have highly complex needs. The nuances of medication management are being better identified, and the interactions of medication management with other forms of treatment are better understood than before.

In addition, the importance of factors such as relationship development and the promotion of the concepts of self determination and development are gradually becoming cornerstones of the work being done with-and-in-support-of these individuals.

On a systemic level, considerable effort has been put forward in the last three years to begin addressing the gap in services that dual diagnosis individuals find themselves in. The system has seen a renewed interest in the concerns of these individuals; thus, a number of targeted initiatives have been developed. These include initiatives by the Ministry of Community and Social Services, such as the development of four networks of specialized care to facilitate service provision for individuals with highly complex needs. In addition, the Ministry of Health and Long-Term Care has funded some specialized case management positions for individuals who fall into this category while the Ministry of Children and Youth Services has begun to fund assessment teams and community based residential services for youth identified as having a dual diagnosis.

Policy and Mandate

Along with these positive developments, there has been an enhanced interest in having the different stakeholders working together. The Networks of Specialized Care, Dual Diagnosis Community Planning tables, and other such planning committees have served to bridge many of the gaps between various service providers and support the concept of integrated and coordinated care for all. It is also encouraging to note that the Ministry of Health and Long-Term Care, Ministry of Community and Social Services and the Local Health Integration Networks have also embarked on a process of review and renewal of the aforementioned guidelines for supporting individuals identified as having a dual diagnosis. This review process and structuring of guidelines will serve to reinforce (among other things) the need for ongoing cross-sectoral planning, as well as the need for agencies to incorporate into their organizational planning the need to support individuals who are identified as having a dual diagnosis.

Moving Forward

Given the above, it is safe to say that in the last three years, substantial movement has taken place to support individuals who are identified as having a dual diagnosis. This positive change has been the result of hard work by ministry structures, agency representatives from across systems, families and the individuals themselves. However, continued work needs to take place. Research needs to continue into the many interrelated aspects of diagnosis and treatment. More targeted education needs to be provided for prospective staff coming into the field through the post secondary education systems, as well as a greater emphasis on ongoing education opportunities for staff who are currently working in support of these individuals. In addition, more work needs to be done in support of community agencies that are willing to make a commitment to work with these individuals and their families. This support needs to take the form of not only financial support but also in terms of expertise, ongoing staff development, and the provision of a safety net for those instances where in fact an individual may require a more intensive level of support than that which the agency may offer. Lastly, these initiatives need to continue to expand to encompass the Ministry of Children and Youth Services and embrace the concept of greater integration of services.

*Arthur W. Mathews is an Administrative Director at the Whitby Mental Health Centre.

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[1] Linsky, Y, Bradely, E. Durbin, J., Koegl, C., Canninus, M & Goering, P. (2003). "Dual Diagnosis in Provincial Psychiatric Hospitals: A population-based study" found that 1% - 3% of the general population has an identified developmental handicap and of those, 20 – 30% have a "dual diagnosis." The population of Ontario is approximately 12 million.

[2] Mathews, A., Brennan, M. et al "An Opportunity for Dually Diagnosed Children, Youth and their families – an opportunity for change", July 2005.

THE DUAL DIAGNOSIS CENTRE: PROMOTING LEARNING AND RECOVERY

Gordon Unsworth* and Ellie Smith**

Since its inception on September 11, 2007, the Dual Diagnosis Centre at Providence Care, Mental Health Services site has served individuals with a dual diagnosis (intellectual disability and mental health illness). A variety of dedicated health professionals, volunteers, and students participate in the Centre with the common aim of improving the overall quality of life for our clients. They assist clients to develop their social and communication skills and those required for daily living. There are many words that can be used to describe the Dual Diagnosis Centre but encouraging, positive, and inspiring are three that instantly spring to mind. An environment is promoted in which participants help and encourage each other in a variety of ways. From assisting others when participating in activities, to just being a friend, the Centre fosters eagerness and willingness to care. It is a positive space of learning and mutual respect where an individual can be him or herself and uniqueness is embraced. More than just a centre, the staff and volunteers work hard to maintain an environment that is fun, creative, and supportive.

The Dual Diagnosis Centre does not just focus on the 'here and now' but provides an opportunity for creativity and innovation. The Centre promotes recovery through activities that develop skills for everyday living. Wishing to encourage functional independence and recovery, the program has created its own form of assessment, called the Life Skills Certificate. This certificate assesses functional independence in areas ranging from washing hands, snack preparation, safe use of appliances, doing laundry and housekeeping, to social interaction. Clients receive a certificate on completion of each of the three different levels. Through this assessment, as well as the utilization of others, such as the Scale of Independent Behaviours – Revised (SIB-R), each client attending the program has the opportunity to be assessed over a wide range of areas. Such assessments provide valuable information as to each individual's strengths and needs. This information can then be utilized for determining appropriate levels of housing for eventual community integration.

The Dual Diagnosis Centre provides one-on-one support as well as a number of group supports, including drama, music, stress management and computer training. Since its beginning, attendance and programs offered have been steadily increasing. The Centre now includes not only staff and clients, but also peer volunteers and volunteers from the community. Plans for implementation of new programs will encourage even more community involvement in the future. A Social Skills group, to include clients of the Centre and community-based clients, is anticipated and therapists from Mental Health Services and Dual Diagnosis Consultation Outreach Team will facilitate this. In April, the new group 'Bodyworks' will focus on health and sexuality.

Embracing the ever-forward movement of technology, the Dual Diagnosis Centre plans to create its own 'Wii-habilitation" program – rehabilitation through the use of a Nintendo Wii. Promoting learning through the use of this technology, participants of the program will develop greater proficiency in areas such as balance, posture, eye-hand coordination and range of motion, as well as general cognition, such as problem solving. It is hoped that Queen's University students will lead the assessment of the clients prior to the Wii-habilitation in areas such as grip strength and eye-hand coordination. They would then monitor the results of the program. This clinic is just one of the ways in which the Dual Diagnosis Centre aims to promote learning and best clinical practice.

Reflections by volunteers, staff and students of the Dual Diagnosis Centre

"It's refreshing to see an interactive environment where the patients have the ability to work with their tactile skills and learn in a fun environment."

"Coming to the Dual Diagnosis Centre is a wonderful experience. It allows you and the clients to forget or set aside their illnesses and enjoy the time here and now. It gives them the opportunity to let go and truly enjoy themselves doing a range of activities and not being judged."

"The Dual Diagnosis Program allows patients to express themselves in an environment that understands, supports, and enhances creativity. Interaction among patients and health care workers promote autonomy that develops skills necessary for everyday living."

"Walking into the Dual Diagnosis Centre while a program is in full swing is a wonderful experience! The sounds of laughter and excitement greet you and a warm, encouraging atmosphere permeates. It is a place of learning, a place of mutual respect; it is a place where an individual can be him or herself and uniqueness is embraced. More than just a centre, the staff and volunteers work hard to maintain an environment that is fun, creative, and supportive. There is a genuine enjoyment that is expressed by all those that attend (both clients and staff) ... it is infectious!"

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[**] Ellie Smith is an Occupational Therapy student from Queen's University, who is currently completing a field practicum at Providence Care - Mental Health Services in Kingston.

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ACCESS TO CULTURALLY COMPETENT SERVICES FOR PEOPLE WITH MENTAL ILLNESS

Marie Kwok[*]

Introduction

In discussing 'access to services,' one must first look at the barriers to service. Among the many barriers, 'communication' is one that has been overlooked by the system. This article will focus on the challenges of communicating with individuals with mental illness from the various ethnocultural communities for both practitioners and the system as a whole. If we consider 'equitable access' to health service as a 'basic right' in Canadian society, then we must attempt to face the challenges head on and to remove the barriers with adequate resources.

Language is Essential to Effective Communication

The most easily understood communication need is language. If two individuals do not speak the same language, they generally will not be able to understand each other. Over the past two decades, the need for language appropriate mental health services when working with non-English speaking individuals has been identified. In an area as linguistically diverse as Greater Toronto and its neighbouring areas, services to consumers in a language they feel comfortable with are still very limited. Commitment from the various levels of government and health service providers to provide mental health services in the language of the consumer is mostly lip service. There was a slight increase in the hiring of staff who speak languages other than English but the fact remains that if you do not speak English, chances are that you will not have access. For people with mental illness who have difficulty with English, calling or walking into most hospitals or community mental health agencies is still as daunting as ever.

Language, Migration and Mental Illness

We have to begin to look at the world from the perspective of an immigrant with mental illness. Imagine yourself trying to grapple with reality, in a foreign culture and environment where everyone is speaking in a language that cannot be understood. Imagine yourself being emotionally distraught and no one understands a word you are saying and everybody is talking at you in an incomprehensible language. Such situations can only aggravate the distress and illness.

For immigrants with a working knowledge of English who become mentally ill, language still remains a challenge. Mental illness and emotional distress can seriously affect a person's proficiency in languages other than their mother tongue. Case studies indicate that immigrants who have been fluent in English and have worked for years comfortably in English, may suddenly have difficulty understanding and speaking English when they become mentally ill or emotionally distressed.

Most new immigrants use English only at work, while continuing to use their native language at home and among their social network. This leads to a compartmentalization of their vocabulary. While they might have a vast work related vocabulary in English, they might not have the vocabulary to talk about their inner thoughts and feelings, and to discuss mental health related issues adequately in English.

Integration or Segregation?

A frequently asked question is: With so many different languages spoken in the Greater Toronto Area, how can we provide for all language minorities? The general approach to this challenge is if we cannot provide for all language minorities, then in the interest of equality, we should provide for none of them. The rationale is that we cannot favour a few minority groups over others. There is a tendency to expect immigrants to 'integrate' into an English speaking society.

To date, the system has yet to adopt a proactive approach in looking at what might be the most cost-effective way to begin to provide language appropriate services for people with mental illness. But is there the political will to address the problem? Are we perhaps blaming people with mental illness from language minorities, particularly immigrants, for not being able to communicate in English? The social and economic cost to society of mental illness is just as great whether the person with mental illness is from a cultural minority or from mainstream Canadian society.

Communication is Not Just a Matter of Language Proficiency

For people with mental illness from ethnocultural minorities, language is usually just the first of many barriers to communication. Even if they have sufficient English, cultural factors often impede communication – that which truly builds connections between service provider and consumer, and helps a service provider to understand the client's situation and condition.

Some aspects of culture, such as ethnic food and costumes, are visible and easily understood. But recent immigrant groups are from cultures with very different world-views, values, religions and social customs. Their conception of self, human relationships, individual, family and community are often very different from those of North American mainstream society, as are their conceptions of and attitudes towards mental health and mental illness.

Our mental health system and its practices, however, are built on the world-views, values and customs of North American/Western European culture, and its conception of mental health and mental illness. Mental health professionals, working according to the rules and regulations of such a system, looking at the world and the consumer through this lens, often completely fail to connect with people from other cultures. This failure can lead to misdiagnoses, inappropriate care, worsening illness, and wasted lives. But more often, people from ethnocultural minorities simply just stay away or back away from a mental health system that seems so alien.

One of the unique features of the culture of North America/Western Europe, for example, is its conception of the individual and of individual rights and responsibilities. Our entire health system is based on this Western concept. The mental health system and its service providers do not seem to understand that concepts of individualism are very foreign to people from most other cultures; rather, people with mental illness from most ethnocultural minorities see themselves as a part of families and communities.

This is just one of many cultural differences.

The Need for Culturally Competent Services

A system that imposes different world-views and values on a consumer can only cause increased conflict in the consumer, and that cannot be conducive to their mental health. The hiring of a few staff from ethnocultural minorities, which is the usual band-aid solution to the problem, cannot really make the system or a service organization culturally competent. Rather, it only leads to frustration for ethnocultural minority staff constrained to work within the current cultural framework. In such a context, under-utilization of mental health services by ethnocultural minorities becomes very understandable. Our uni-cultural mental health system forms a wall against access to mental health service for people with mental illness from ethnocultural minorities.

Recent waves of immigrants are all from countries with cultures that are vastly different from mainstream North American culture. The top five countries of origin for recent immigrants are all Asian. As visible minorities coming from countries with very different cultures and languages, they face far greater challenges during their settlement process than previous waves of immigrants. These challenges can lead to mental health stresses that can become a contributing cause to mental health problems.

Culturally sensitive mental health promotion programs provide a channel for early identification and early intervention to prevent mental health difficulties. This in turn would open doors for easier and appropriate access to mental health services. Immigrants do see mental health and mental illness from different perspectives. Culturally sensitive prevention and promotion programs are cost effective for the system in the long run. It is also an efficient way to address barriers to access issues.

Engaging Communities

We must begin to engage ethnocultural communities in the planning, implementation and evaluation of the mental health system, if we are to work towards a culturally competent system with equitable access for all. To engage them, the system needs to reach out to them by respecting their world- views, values, customs and concepts of mental health and mental illness, while truly listening to their needs and concerns. More importantly, the system has to be able to follow through in implementing agreed upon solutions from engagement processes.

For many ethnocultural communities, mental illness is a taboo topic and stigmatization is far more intense and deep-seated than among the general Canadian public. So, to engage them in any discussion of mental health and mental illness, it is often necessary to begin with related health and social issues, and gradually build their comfort level in discussing mental health issues and to reduce stigmatization in the community. We have to bear in mind that if mental illness cannot be discussed in a community, then people from that community are hardly likely to seek help for mental illness. A better understanding of mental health and a higher degree of acceptance to mental illness would also facilitate more effective approaches and options in mental health care.

Access is not only about availability. Accessibility is only real when people are able to use a service. Ultimately, it is only through working with each community that we can develop mental health services that are truly culturally competent and accessible to that community.

Summary

Accessibility to the mental health system by non-English speaking individuals living with mental illness is a multilayered challenge. Over 55% of the population residing in Toronto and its surrounding areas are newcomers from all parts of the world; yet over 90% of our services are offered in English only. Addressing access to service barriers requires a firm commitment from the system, service providers and practitioners to reflect and review their interpretation and understanding of mental health as well as those of newcomer communities. A better understanding and agreement on how we are to define 'culturally competent' services is the first fundamental step to making change.

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NAVIGATING THE SOCIAL AND CULTURAL CONTEXT: SERVING NEWCOMERS

Deqa Farah[*] and Zarsanga Popal[**]

Background

Conditions in many parts of the world – including war and displacement, political conflict, and economic insecurity – have forced individuals and families to leave their homelands behind and settle in Canada. Many are refugees and must deal with the additional trauma of forced migration. They may suffer the lasting effects of post-traumatic stress as a result of war and violence in their homelands while they deal with resettlement and integration stress in Canada. As newcomers to a new land, they experience isolation, discrimination, alienation, and displacement. These psychological and emotional factors are combined with the adversity faced by immigrants and refugees in accessing jobs, housing, and social services.

Newcomers to Canada come from a variety of countries with different cultures and languages. Some come from minority groups within those countries, such as Tamils from Sri Lanka or Karen government-sponsored refugees from Myanmar (Burma). The country of origin of newcomers changes from year to year in response to factors such as war, natural disaster, economic and political upheaval, and the persecution of particular groups. This ever-changing range of characteristics and experiences of newcomers to Canada presents a major challenge with respect to providing newcomer communities with effective mental health services.

Barriers to Access

Sana Halwani has aptly observed that "to a Canadian-born, white, middle class individual, the health care system, though admittedly imperfect, provides appropriate services in an appropriate context. To a member of a visible minority, to a person who speaks neither official language or to a recent immigrant, the health system can be an incredible obstacle course."[1] The following discussion identifies some of the most challenging obstacles faced by newcomers in accessing mental health services. They are broken down into five barrier levels – individual, community, service provider, organizational, and systemic – although in reality these barriers are dynamic, interactive, and often span multiple levels. It is important to note that this discussion is by no means exhaustive.

Furthermore, despite this article's particular focus on newcomers, these challenges are highly relevant to members of other marginalized groups as well:

- **Individual barriers**: Many newcomers are unaware of the mental health services that are available to them. Stigmatization, discrimination, and alienation may also keep newcomers from accessing services.
- **Community barriers**: Family, religious and traditional practitioners, and settlement agencies are often newcomers' first points of contact. As a result, families that may share some of the trauma of migration are often overburdened, as are settlement agencies that lack both the mandate and the resources to serve individuals with mental health needs.
- **Service provider barriers**: Providers may exhibit bias or discrimination as well as a tendency to categorize all of the various mental health issues of refugees simply as "post-traumatic stress disorder." This can oversimplify the complex experience of refugees by ignoring the trauma resulting from the experiences of racism, poverty, isolation, and marginalization that are often inherent in the resettlement and integration process.
- **Organizational barriers**: The tendency of mental health service agencies to develop stand-alone projects with short-term, ad hoc funding and uncertain futures means that programmes are often lacking in consistency and efficacy. Tokenism also keeps organizations from achieving real outcomes and from being accountable to clients and communities. By hiring small numbers of workers who speak multiple languages or who come from certain communities, agencies place the responsibility for understanding and articulating the dynamics, history, culture, language, and current group status of target communities on a few individuals, rather than developing these competencies within the organization as a whole and ensuring that services are truly accessible and appropriate for all clients.
- **Systemic barriers**: Exposure to mental health services is limited in part by the lack of collaboration between immigrant and mental health organizations. Many newcomers are also overwhelmed by the complicated paperwork, long waiting lists, eligibility criteria, and intake processes that characterize our mental health system. This situation is often compounded by the reality that they enter the mental health system by way of the legal system or involuntary hospitalization. In addition, most services require that clients have a formal diagnosis, which many newcomers lack as a result of limited use of primary care or hesitancy to disclose mental health issues to a doctor due to potential stigma or fear it might negatively impact their immigration status. Furthermore, the federal government does not include mental health issues in programmes to assist new immigrants so there are almost no services available for people who have experienced resettlement and migration stress. Newcomers who require counselling must often face the financial burden of accessing fee-based services.

Developing Appropriate Services

Knowing the challenges newcomers face, how do we minimize barriers and make real changes within the mental health system in order to create health outcomes that are more equitable for all consumer/survivors?

Community Resource Connections of Toronto's Example

Starting in the late 1990s, Community Resource Connections of Toronto (CRCT) began exploring the ways in which it could best adapt to the changing face of Toronto. We came to realize that what was required was a transformation of our organizational culture. This meant making our services available to consumer/survivors who, in the past, would not have had access to our services. CRCT's approach is built on the recognition that discrimination based on race, ethnicity, culture, religion, country of origin, gender, disability, sexual orientation, language ability, socioeconomic status, refugee status, and other markers can have a direct impact on health and well-being and hinder access to services.

In 2003, through a grant from Department of Canadian Heritage, we began to apply organizational-change strategies based on access and equity across the entire agency. We created an Increasing Accessibility Committee, and in 2004, in conjunction with Tina Lopes and Barb Thomas, we adapted the following organizational statement:

> Organizational change for access and equity is not neutral. Change towards equity is based on an assumption that inequitable power and access to resources exist in our society, and therefore exist in all our organizations. Unless inequity in all its forms is actively challenged, it reproduces itself whether we intend it to or not.

Committing ourselves to equitable power and access to resources on a broad scale meant examining the day-to-day practices of every aspect of CRCT's work, including service provision, programme development, employment practices, management, and governance. In short, we initiated a process whereby we consciously observe our own actions, identify challenges, and develop tools and practices to be used across the organization to address the barriers we encounter.

One of our major areas of emphasis is information development and dissemination. We strongly believe that appropriate responses to the mental health needs of individuals dealing with mental health challenges start with providing culturally and linguistically appropriate information. This can include:

- Providing information in different settings, such as ESL (English as a Second Language) and LINC (Language Instructions to New Canadians) classes, drop-in centres, Community Health Centres, and shelters; partnering with refugee welcome houses.
- Providing information about mental illness in simple language.
- Providing regular updates about available services, training, forums, and workshops for newcomer communities.
- Organizing accessible training events in partnership with other providers.
- Developing health promotion strategies to address issues of stigma through local ethnic community media.
- Collaborating with ethno-specific services to train service providers about the refugee experience, the barriers newcomers face, and strategies for removing these barriers.
- Starting a dialogue among mental health agencies to develop ways of addressing the needs of underserved communities in their catchment areas.
- Hiring diverse staff members who are culturally and linguistically competent.

One outcome of this approach is CRCT's publication entitled Navigating Mental Health Services in Toronto: A Guide for Newcomer Communities, which was written in English and has been culturally translated into Dari, Pashto, Somali, Tamil, and Urdu. The two-year, multiphase development process centred around discussions with consumer/survivors, family members, communities, service providers, and mental health professionals to determine how best to meet the needs of our target populations. In consultation with these stakeholders, we were able to determine the specific information that was required, the cultural perspectives and competencies with respect to mental health that we needed to address, and the best strategies for making this information accessible to the identified populations.

CRCT is applying these lessons in the realm of service delivery by matching clients with linguistically and culturally appropriate case management in both Tamil and Somali. We work to maximize service provision by partnering with organizations that provide settlement services and by targeting our own outreach toward particular communities. This way, our staff are able to understand the cultures of our clients and build trust within their communities.

Key Lessons

Commitment

Change aimed at effective mental health service provision to diverse consumer/survivors requires a strong commitment. It is essential to cultivate buy-in with clients, front-line staff, management, board members, and other stakeholders and to commit organizational resources to research, evaluation, and training. It is also vital to devise comprehensive health equity action plans with timelines and clear lines of responsibility and accountability. Finally, it is essential to recognize and allow for the reality that meaningful change takes time. This includes the process through which the organization defines new internal sets of relationships, strategies, and programmes as well as its external presentation of services and development of visibility and trust within the community.

Collaboration

Change aimed at effective mental health service provision to diverse consumer/survivors requires a broad vertical and horizontal focus. Vertically, change must take place at all levels where barriers are present: individual, community, service provider, organizational, and systemic. Horizontally, partnerships and alliances with other organizations are necessary to meet clients' various needs. Mental health providers and settlement agencies can complement each other's services, and they can set strategies and develop ways of addressing barriers by establishing creative partnerships.

Cultural Competency

Change aimed at effective mental health service provision to diverse consumer/survivors requires the development of a high level of cultural competency. Service providers must be educated around stigma and the perception of mental illness in newcomer communities. In addition, the influence of family and friends must be understood and addressed appropriately. The concepts of community services and other forms of mental health service delivery must be communicated effectively, as they may be unfamiliar to many newcomers. In sum, as organizations develop programming and outreach models, it is essential that they do so with an understanding of the linguistic, cultural, and experiential components that will be necessary to ensure that newcomers will be able to understand and access services.

Conclusion

In conclusion, CRCT's experience can be applied within the broader system as service providers adopt new approaches to recognize and address the unique needs of newcomer communities. First, organizations must be willing to identify the particular unmet needs within their communities and to reach out to them. At the same time, a transformative process within each organization itself is required so that its staff, programmes, and board are reflective of, and accessible to, diverse communities. Finally, organizations must possess a willingness to examine the dynamics of power and marginalization which create access barriers at various levels, and they must be committed to challenging those dynamics. By applying these lessons (and later sharing some of their own lessons), organizations can work together toward our common goal of health equity – not only for newcomers to Canada, but for our broader community as well.

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[1] Sana Halwani (December 2004), Race Policy Dialogue Conference Paper

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ACCESS TO MENTAL HEALTH SERVICES AND SUPPORTS FOR RACIALIZED GROUPS

Aseefa Sarang* and Kwame McKenzie**

Introduction

A major challenge in high-income countries during this period of globalization has been the development of mental health services that meet the needs of their increasingly diverse population.[1]

Canada is home to an ever-changing population. Immigration is now the main driver for growth and the percentage of foreign-born people is the highest that it has ever been. How should Canada meet the challenge of producing equitable mental health services for its diverse population? In keeping with the celebration of the 25th anniversary of the Psychiatric Patient Advocate Office (PPAO), we will honour the past but given the urgency of this issue, we will spend more time considering the future.

Honouring the Past

In 1988, the report of the Canadian Task Force on *Mental Health Issues Affecting Immigrants and Refugees* was published.[2] It noted high rates of mental health problems in immigrant groups, particularly poor access to care and poor quality of care received. The group made several recommendations, including the following key suggestions:

- Better cross-cultural training of existing and new staff;
- More accessible services for immigrants that provide evaluations of their effectiveness;
- More health promotion;
- Increased hiring of ethnic minority staff by social, health, and mental health service agencies
- A curriculum for training interpreters used by mental health services; and
- Consideration of funding of ethno-specific rehabilitation and reintegration facilities.

Though these recommendations refer to immigrant and refugee groups, they resonate with the needs of racialized groups.[3]

Over the last decade, Across Boundaries: An Ethnoracial Mental Health Centre, has been involved in research investigating the experience of racialized groups using services in Toronto. Its methodology included a literature review and interviews with service users, their families and service providers and was the result of collaboration with others interested in this topic.[4] People who used the services said that encounters with the mental health system were almost exclusively negative when access and quality of care were considered. They cited Eurocentric models and values as barriers to getting services in a timely and appropriate manner. People felt isolated, alienated, and silenced by the high and frequent prescription of medication when they would rather be listened to and heard. Users felt misunderstood, stigmatized, helpless, hopeless, fearful and confused. Many regretted having sought mental health services in the first place - particularly with regards to psychiatric and hospital-based services.

Service providers felt unsupported by upper management to challenge an organization's practice and service delivery models. Those who did try to make a difference feared that they may be marginalized at work. They said that they were expected to take on the role of the antiracism educator or trainer at their organization. They criticized their organizations for superficial adoption of cultural competency and anti-racism policies.

Both groups said that the mental health system and racism interacted to prevent the funding of services that are considered by racialized groups to be effective and/or appropriate.

These findings are worrying but, given the literature on this subject internationally, they are not surprising. They reflect the need for comprehensive reform throughout health delivery including: information and understanding of racialized groups and their determinants of health; prevention strategies; access to services; clinical practice; and funding streams.[5]

Looking to the Future

Pathways to Care[6]

It is difficult to understand and negotiate the complex network of choices that is the Canadian health system. If you add cultural ideas of who should be offering care, what that care should look like, the ever-present problem of stigma and the difficulty of getting a primary care physician, it is clear that people from racialized groups could easily be disadvantaged. Research demonstrates that people from racialized communities experience many barriers when trying to access mental health services. If traditional routes to mental health care are not taken, the risk of entering the criminal justice system is increased.[5]

A concerted effort at a systems level is needed to improve access to services for racialized communities. A systems approach would consider attempting to increase the community's knowledge of the existing services and diversifying access to them while understanding community needs and developing the types of services they want deployed. Existing more flexible models such as outreach services, community-based and run support services and one stop health and social care services could be expanded, thereby more traditional mental health service providers could improve their cultural capability.

However, there is no point to racialized groups having equal access to care that is not effective. Because of this, discussions on equity also include consideration of how to make services work as effectively for racialized groups as other groups.

Quality of Care

Once in the system, people from racialized groups receive care that is not the same as that of the mainstream populations. There is a general lack of understanding of their needs, perspectives, models of illness and models of wellness. On top of this, popular stereotypes, particularly of black men, portray racialized individuals as more dangerous, violent and less compliant with treatment. This can produce a toxic interaction which undermines the service and service user partnership, leading to more coercive care, higher medication doses and poorer outcomes.[5]

Some have taken a piece-meal approach to solving this problem. Unfortunately, well-meaning but isolated gestures such as hiring someone from a particular community, producing material in a particular language or providing interpreters are surface level solutions that will not, by themselves, bring about equity. Moreover, they take away the responsibility of an organization to reflect on its values, philosophy, and to develop the kind of the coordinated, long-term changes needed to be fully accessible.

Many agencies and institutions now offer services that are "inclusive," "culturally competent" or "diverse." To continue to make this claim, they need to carefully analyse the root causes of disparities and then offer treatments or therapies that are useful from the perspective of those who need them.

Elements of Effective Quality Care

So where should we start? There needs to be an expectation that comprehensive and coordinated care has to be provided by all and not just ethno-specific agencies.

We should start with an acknowledgement that the problem does not lay with the individual but with our systems of care. We need to take a good look at how we can improve our services at both at an inter-agency and intra-agency level. There needs to be commitment to making the necessary changes no matter how uncomfortable those changes may be and this commitment needs to come from the highest ranks of decision makers. Appropriate criteria need to be developed and benchmarks need to be set, along with the necessary levels of funding.

We need to challenge the attitudes and stereotypes inherent in our society and practice. Racialized communities should be identified and worked with, not as special interest groups but as core members of the fabric of our society. With our understanding of the determinants of health and the way that illness is structured and perpetuated, we should be able to see that advocacy is a legitimate and important tool for prevention by improving the lives of racialized groups with mental health issues.

Holistic Approach

The individual is not the sum total of his/her illness and the illness is but one component of the person's life. Issues such as housing, employment, family reunification and spirituality may be a priority in the person's life and addressing those needs first or in conjunction with their illness, may be far more effective than concentrating on illness management alone. People from racialized communities have many intersecting concerns; a holistic approach recognizes the interdependence of the spiritual, emotional, mental, physical, social, cultural, linguistic, economic and broader environmental aspects of health.

Anti-Racism/Anti-Oppression Approach

Racism is a social determinant of health and should be included in conversations on service delivery. Not naming racism as a root cause of disparity does a disservice to the population. It also takes away from our ability to identify ways of providing appropriate services. Using an anti-racism-anti-oppression approach is important to clearly understanding the impact of power, privilege and discrimination.

Organizational Change

Agencies need to be more engaged with their communities. In order to develop services, we need to know our demographics, catchment area, populations, as well as their customs, languages, and health care needs. We need to consult the community and bring members of the community onto our boards, management and frontline staff. Education and training should be provided to all staff around appropriate core competencies. Hiring staff that are not only from the relevant communities, but who also have a good understanding and analysis of the community for which they are being hired, can help to develop positive relations with the community.

Complementary Models of Care

We should move from simply deploying traditional western models of care towards inclusion of other models, such as acupuncture, yoga and ayurveda, which have long histories and are considered efficacious by diverse communities. Not having access to these treatments under the publicly funded health system sends a very clear message about how Canadian society values these approaches which are the first choice of treatment for many people. Giving clients a choice goes a long way towards making the service truly *culturally appropriate*.

Research

Funding decisions are based on information. People from racialized communities are under- represented in research studies. Further, such work rarely investigates health from the perspective of racialized communities. Thus, the available evidence is thin. If inadequate evidence is actually used, ineffective services will result.

Though mainstream research under-represents racialized communities, there is growing grey literature and work by community groups, policy makers and social scientists. Transferring this knowledge into policy may be key to funding appropriate and responsive services.

Conclusion

There is much evidence of the gaps in services but also many effective ways of addressing them. We need to provide a collective will to make the needed investments and to ensure that racialized communities receive meaningful access and supports for their mental health needs. As the Canadian population continues to change, this is no longer an option but a necessity.

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1 Standing Senate Committee on Social Affairs, Science and Technology, *Interim Report: Mental Health Policies and Programs in Selected Countries*, November 2004.

2 Canadian Task Force, *After the Door Has Been Opened: Mental Health Issues Effecting Immigrants and Refugees in Canada*. 1988.

3 There are many terms used such as "recent immigrants," "refugee and asylum seekers" and "established ethno-racial groups" all of which refer to different groups that may have different service needs. Here, we focus on those who are from racialized groups (people who suffer discrimination because of their race). Studies have shown that they are the most marginalized group because they are not able to participate or contribute fully as equal members of society and because racism is a risk factor for mental illness.

4 Across Boundaries: An Ethnoracial Mental Health Centre, *Striving for Best Practices and Equitable Mental Health Care Access for Racialized Communities in Toronto*, 2006.

5 Department of Health. Delivering race equality: an action plan for improving services inside and outside mental health care and the government's response to the independent inquiry into the death of David Bennett. London: DoH, 2005. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4100773.

6 Pathways to care refer to the route we take through the maze of professional and non professional options to find help for our problems. Research demonstrates that people from racialised groups have different pathways to care when compared to other groups.

SENIORS' MENTAL HEALTH MATTERS!

Kimberley Wilson*

For many years, the aging of the 'baby boom' generation has been discussed and debated, at times in an apocalyptic manner. The era is now upon us as the earlier end of the baby boom cohort has entered their sixties. Has all the debate and discussion prepared government, the health care system and support structures in Ontario and Canada for an aging population?

Seniors constitute one of the fastest growing population groups in Canada. There are over 4.3 million Canadians aged 65 and older,[1] and this number is expected to rise significantly as the baby boomers age. It is important to note that seniors are not a homogeneous population. There can be dramatic differences in those individuals aged 65 and those in their eighties or nineties. As well, due to co-morbidities, coping mechanisms, and resiliency factors, there are some adults who are not yet 65 that may require the support and services geared to seniors. This large variation in needs and supportive services is also confounded by the diversities of culture, religion and sexual orientation as found in this generation and others.

As people age they are more likely to have chronic illnesses, with 87% of those aged 65 and older reporting living with at least one chronic condition.[2] Aging, along with some of the life transitions that are common in older age, act as a risk factor for a variety of mental illnesses.

Overview of Seniors' Mental Health Issues

Currently, one in five Canadian seniors is reported to be living with a mental illness.[3] Many researchers believe this number is a gross underestimate and does not reflect the true picture of seniors' mental illness in Canada. The most common mental health problem for older adults is depression, with approximately 20% of all seniors experiencing symptoms of depression.[4] What is more alarming, however, is that the incidence of depression in seniors living in long-term care settings is three to four times higher than that of the general population.[5] Despite the high incidence of depression and its prevalence, depression should not be considered a normal consequence of aging!

Often referred to as the 3Ds, depression, delirium and dementia are very common illnesses that afflict those over the age of 65. These three conditions are often discussed in combination, as their symptoms may mimic one another, complicating diagnosis. Reported rates of delirium can be as high as 50% of all older persons admitted to acute care settings, and this number rises to 70% of patients aged 65 or older admitted to an intensive care unit of a hospital.[6] In many cases of delirium, the symptoms go unnoticed and remain untreated, resulting in worsening of symptoms and an increased risk for physical and mental deterioration.

In many cases of depression and/or delirium, the symptoms may be misdiagnosed as dementia, a condition most often associated with late life. People who suffer from dementia face memory impairment and in many cases also have behavioural symptoms which can include agitation, aggression, wandering and sexually inappropriate behaviours.[7] Alzheimer's disease is the most common form of dementia, with one in thirteen Canadians over the age of 65 living with a diagnosis of Alzheimer's disease or a related dementia.[8] Risk increases with age, as one in three Canadians over the age of 85 will be diagnosed with Alzheimer's.[9] Further information on Alzheimer's disease and related dementias can be found within this publication, in an article written by Scott Dudgeon, "The Perfect Storm."

Although knowledge continues to increase about the prevalence of mental illness in seniors, and awareness is raised, there are still many issues that remain hidden in the shadows. It is often surprising for people to hear that the 1997 suicide rate for older Canadian men was nearly twice that of the nation as a whole.[10] As well, the lethal potential for self-harm behaviour (versus non-lethal self-harm behaviour) increases with advancing age for both men and women.[11] With the aging of the baby boomers, a cohort which already has high rates of suicide, it is likely that without prevention there will be a greater number of older lives lost to suicide.

While the statistics around late life suicide can be surprising, many people are also shocked to learn that gambling and addictions are a very real problem for older adults. While some adults may begin having problems with substance use in later life, it is important to remember that personalities do not change with aging, and the aging process alone does not end substance use or gambling. In fact, 6 to 10% of older adults have problems with alcohol misuse, a statistic which is similar to the adult population.[12] What is of particular concern is that aging affects alcohol sensitivity which may leave an older adult more vulnerable to the impact and negative effects of alcohol consumption.

In addition to the above-mentioned common mental illnesses associated with later life, it should be noted that there is a unique population of those aging with severe and persistent mental illness including schizophrenia, bipolar, severe depression and generalized anxiety disorders. This population remains understudied and at this time there are inadequate supports and a lack of understanding of the needs of this population.

Why Does Seniors' Mental Health Matter?

The mental health of *all* Canadians is important, including those who are over the age of 65. Mental illness is not a normal consequence of aging. All seniors have the right to, and deserve to receive services and care that promote their mental health and responds to their mental illness needs.

There are well documented economic burdens of mental illness, both direct and indirect. The Alberta Mental Health Board and the Institute for Health Economics estimates that the economic burden of mental disorders in Canada is nearly $10 billion.[13] With seniors being the largest cohort in coming years, the proper assessment, treatment, management and service provision will undoubtedly increase this number.

Many seniors with mental disorders require assistance to remain in their home, which often falls onto spouses or children, most often women. Not only does this informal care save the health care system billions of dollars, but it also places them at risk for their own mental illness. For example, up to half of the primary caregivers for someone with Alzheimer's disease develop significant psychological distress.[14]

Stigma unfortunately remains a barrier to accessing care and information, and seniors face the "double whammy" of the stigmas of aging and the stigmas associated with mental illness. The issue of stigma must be addressed with both the general public and those in the health care system to ensure that seniors' mental health does matter. While there are numerous arguments why mental health matters for seniors, the bottom line is that it is an issue of human rights. To not provide services and support for seniors would be an issue of discrimination and people across the lifespan deserve to be treated with dignity and respect.

What's Being Done?

Currently, there are many committed individuals, organizations and partnerships dedicated to improving the mental health of seniors across the country. This is an exciting time for mental health in Canada with the release of the report "Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada" in May 2006 and the establishment of the Mental Health Commission of Canada. Both the report and the Commission have recognized that seniors are a unique population with specialized service issues and outline action steps to address the gaps in the current system. Additionally, the Canadian Coalition for Seniors' Mental Health[15] recently released the first ever national multidisciplinary best practice guidelines for the assessment and treatment of seniors mental health issues. The implementation of these evidence based recommendations and guidelines would help to standardize and improve the care of Canadian seniors.

What Can be Done?

Although progress is certainly being made, ongoing advocacy is required to ensure that seniors and their mental health are considered a key Canadian health and wellness issue. As the baby boomers near their senior years, system changes are still required to meet the needs of the aging population. Increased capacity and training in the field of geriatrics is desperately needed and government support will be required to allow for this movement. The current rates of mental illness are high in the seniors' population, and unique needs of the cohort that is moving into their later years must to be kept in the forefront of planning and policy decisions.

*Kimberley Wilson is Executive Director of the Canadian Coalition for Seniors' Mental Health.

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2 Non-Communicable Chronic Illness. Statistics Canada. Last modified 08/10/2004. www43.statcan.ca/02/02b/02b_006_e.htm

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4 Canadian Coalition for Seniors' Mental Health. National Guidelines for Seniors' Mental Health: The Assessment and Treatment of Depression. 2006. Toronto(ON): CCSMH.

5 *Ibid.*

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7 Canadian Coalition for Seniors' Mental Health. National Guidelines for Seniors' Mental Health: The Assessment and Treatment of Mental Health Issues in Long Term Care Homes (Focus on Mood and Behaviour Symptoms). Toronto (ON): CCSMH.

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10 Canadian Coalition for Seniors' Mental Health. National Guidelines for Mental Health: The Assessment of Suicide Risk and Prevention of Suicide. Toronto (ON): CCSMH.

11 *Ibid.*

12 The CAMH Healthy Aging Project. Responding to Older Adults with Substance Use, Mental Health and Gambling Challenges. 2006. Toronto (ON). CAMH.

13 Alberta Mental Health Board and Institute for Health Economics. Mental Health Economic Statistics in your Pocket. Alberta: 2007.

[14] Geriatric Mental Health Foundation. Caring for the Alzheimer's Disease Patient. 2003. www.gmhfonline.org/gmhf/consumer/factsheets/caring_alzheimer_disease.html.

[15] With over 90 organizational and 900 individual members, the Canadian Coalition for Seniors' Mental Health was established in 2002, with the mission to "promote the mental health of seniors by connecting people, ideas and resources." For more information or to become a member visit www.ccsmh.ca.

THE PERFECT STORM

Scott Dudgeon*

For 25 years, the Psychiatric Patient Advocate Office (PPAO) has been speaking up for people with mental health problems, addressing such issues as the need for peer support, housing, income support, and access to new treatment modalities.

While advocacy on behalf of individual psychiatric patients is a central role, it is through their systemic advocacy, working on issues vital to the rights and recovery of people dealing with mental illness, that I have come to know and respect this important program.

Their history to date has paralleled Canada's history of right's advocacy and mental health reform, from the advent of Canada's *Charter of Rights and Freedoms*,[1] through the various crises that have driven the history of mental health reform to the establishment of the Mental Health Commission of Canada.

What's in store for the PPAO over the next 25 years? I would submit that the principal preoccupation of the office over the next generation will be rights and advocacy issues associated with seniors' mental health. We will be dealing with a perfect storm of historic proportions over the next 25 years and the PPAO will need to be vigilant to avoid storm damage. (A perfect storm is the simultaneous occurrence of events which taken individually would be far less powerful than the result of their chance combination.)

The first contribution to the perfect storm I'm going to describe is the global crisis in health human resources. In Canada, 1.5 million people are employed in health services, which equals 10% of the Canadian workforce. Right now, 3.6 million Canadians report that they do not have a family physician. Canada ranks 26 of 30 OECD countries in terms of physicians per 1,000 population. The Canadian Nurses Association projects a shortage of 78,000 registered nurses by 2011.[2] This problem is replicated across the spectrum of health care workers – psychologists, public health inspectors, paramedics, physiotherapists, pharmacists and others. It is becoming patently obvious that, even if demand for services were to remain constant, we do not now have enough health professionals to do the work, and the problem is only going to get worse.

Cliff Halliwell, Director-General responsible for policy in the federal Ministry of Human Resources and Social Development says, "While population aging will inevitably increase service demand, its effects will be most immediate on health human resources supply – the 'bow wave' of population aging." In this decade alone, many health care workers will retire and will need to be replaced at a time of overall slowing in population and labour force growth.

From a policy perspective, the health human resources crisis has had a lot of scrutiny without yet getting much traction. It is reasonable to say we got into this mess, largely through policy (e.g., downsizing in the 1990s and efforts to limit the supply of physicians) but we have not found the policy route out of it. The Romanow Commission[3] has weighed in, as did the Kirby Committee.[4] The issue has been front and centre in First Minister discussions and is a key feature of the Health Accord. Yet there are no breakthrough solutions are on the horizon.

The high pressure system of population aging has driven the scarcity of health human resources. The aging of the Canadian population, according to Statistics Canada, will start to really accelerate in three short years, when the first baby-boom cohort (born in 1946) reaches the age of 65. This pattern is projected to last another 20 years, when seniors will account for 25% of the total population. This will be almost double their current proportion of 13%.

Population aging is also a central feature of the second ingredient in the perfect storm I am describing – specifically, the increasing prevalence of dementia. Alzheimer's disease is the most prevalent of a number of disorders known collectively as dementias. After cancer, there is no disease that worries Canadians more as they age. It attacks those very attributes that define us as autonomous, functioning people. The disease erodes independence and its associated mental deterioration leads to escalating levels of caregiver support. With increasing behavioural problems, there are increasing admissions to long-term care facilities. Because of the long periods of dependence associated with Alzheimer's disease, it has the potential to devastate families and destroy the health of family caregivers.

Dementia appears to occur at the intersection of genetic endowment and the interactions of risk and protective factors. Most prominent of many risk factors is aging – prevalence increases sharply with age. For instance, 2% of people 65 to 74 have Alzheimer's disease, 19% of people between 75 and 84, and 42% of people over 85. Worldwide, prevalence is doubling every 20 years.[5]

Approximately half a million Canadians have dementia, most of which is attributable to Alzheimer's disease. Within a generation there will be one million people in Canada with dementia. In the absence of a national dementia control strategy, this disease has the potential to overwhelm the Canadian health care system, and Canadian society. This strategy needs to be grounded in a solid understanding of the epidemiology of the disease, along with its economic impact – now and in the future. The strategy also needs to be comprehensive with respect to prevention, diagnosis, treatment and care for caregivers and research.

So, the climate of population aging, especially with those baby-boomers now entering their 60s, has created two simultaneous events – increased prevalence of dementia with the associated demands placed on the health care system, and a critical shortage of health human resources necessary to manage this epidemic.

But wait, there's more.

I would submit that the third ingredient of this perfect storm is the stigma associated with both aging, and mental health problems such as dementia. This stigma makes it difficult to seek treatment (or to encourage family members to seek treatment), to maintain the social connections so vital to good mental health, and, in terms of policy, for politicians and bureaucrats to see the enormity of the problem. There is still a tendency to think of dementia as a quaint forgetfulness – a view entirely at odds with the reality of its being associated with a horrible and protracted death. The worst kind of stigma associated with aging is the old car syndrome – why put new tires on a car that's past its useful life? I was recently asked by an interviewer from a prominent national media outlet if it's really worth investing in a dementia strategy if these people are near the ends of their lives anyway.

The answer, of course, is yes.

So, what do we do? The Alzheimer Society will continue to advocate on the basis of an economic argument – the cost of prolonged nursing home care combined with the lost income of wives and daughters who have interrupted their careers to care for a family member with dementia – while also speaking about the inherent dignity of people at all stages of their lives. The Canadian Coalition on Seniors Mental Health will continue to advocate for better support for the broader mental health issues borne by older Canadians – delirium, depression and high suicide rates. It is estimated that one million of the four million Canadians currently over the age of 65 have a mental illness and that, with an aging population, depression will soon be the leading cause of disability in Canada. We work hard to help the public and their political representatives understand that dementia and other mental health problems are not a natural consequence of aging – and to understand that mental health problems of the elderly are as legitimate, as treatable, and as worthy of policy attention as any other health issue borne by any other Canadian.

We count on the PPAO to see the hazards associated with this perfect storm of increased need for diagnosis, treatment and care by older people with various mental disorders on the one hand, and the inadequacy of health human resources to do this work on the other hand. We also hope the PPAO will anticipate these hazards and focus both its individual and systemic advocacy on the rights and empowerment issues that surely will accompany this perfect storm.

[*] Scott Dudgeon is Chief Executive Officer at the Alzheimer Society of Canada.

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1 Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

2 Canadian Medical Association, Environmental Scan, 2007.

3 Building on Values: The Future of Health Care in Canada, *Report of the* Commission on the Future of Health Care in Canada, 2002.

4 *The Health of Canadians - The Federal Role, Volume Six: Recommendations for Reform*, Standing Senate Committee on Social Affairs, Science and Technology Study on the State of the Health Care System in Canada, 2002.

5 Alzheimer Society of Canada, 2007.

A PERSPECTIVE ON THE USE OF PHYSICAL RESTRAINTS IN ONTARIO LONG-TERM CARE HOMES

George H. Parker*

With an aging population, dementia has become an increasingly common condition among residents in Ontario's long-term care homes. The Ministry of Health and Long Term Care has estimated that six out of ten - some forty five thousand residents - show signs of this condition.

Despite its prevalence, the Ministry has not come to grips with a fundamental aspect of this group's accommodation: achieving an appropriate balance between the measures needed to ensure their *freedom*, and the measures needed to ensure their *safety*. As the substitute decision maker for a resident with dementia, it has been my experience that the value of preserving the freedom of these residents has been *heavily discounted*, resulting in a bias towards the use of safety measures – that is, the imposition of physical restraints.

In the long-term care context, "physical restraints" typically refers to a lapbelt which the resident is not capable of undoing, thereby confining them to a wheelchair. The imposition of restraints may also involve the administration of sedating medication, in order to ensure that the resident will accept the confinement. In arriving at such a "solution," the value of preserving the freedom of dementia residents has been discounted, in several different ways.

First, freedom has been discounted by the failure to provide an appropriate physical environment. The environment in the homes is still geared towards the delivery of nursing care to residents with physical health problems. Little attention has been paid to the environmental needs of physically able residents with mental health problems, such as dementia. Even within the "secure units," the outfitting and interior zoning are not conducive to preserving the freedom of this group of residents. Considerable emphasis has been placed on the *seclusion* of these residents, but very little on promoting their *mobility*.

Second, freedom has been discounted by the lack of precision in legislation pertaining to restraint. The legislation allows for the use of restraints if the resident is at risk of injuring themselves, or causing injury to others. But the legislation does not distinguish between two very different types of risk. The first is the risk presented by a dementia resident who cannot interact safely with their environment (equipment, furniture, fixtures, finishes, other residents, etc.), while the second is the risk presented by a resident who has lost the physical ability to walk in a safe manner. By allowing the home operator to request a restraint order simply on the grounds of "safety," without specifying the nature of the risk, the Ministry is downplaying its responsibility for specifying a safe ambulatory environment for dementia residents.

Third, freedom has been discounted by the home's ability to make restraint a condition of residency. This Ministry provision leaves the physician and the substitute decision-maker with little choice but to agree to the imposition of restraints, since leaving the home is seldom a realistic option for a resident with dementia. It effectively allows the home operator to be the *final arbiter* on the imposition of restraints - an unethical situation, since the use of restraints provides an economic benefit to an owner who is often a for-profit corporation.

Fourth, freedom has been discounted by the lack of services provided to restrained residents. Once restrained, residents are not provided with any Ministry-regulated release. The home is required to "check and reposition" a restrained resident every hour, but this is a technical procedure performed while the resident remains seated in their wheelchair. The home may offer restrained residents an assisted walking program, but this is essentially a good will effort, since its delivery is not a "compliance issue" with the Ministry.

Fifth, freedom has been discounted by handing the authority to impose restraints to medical practitioners. This delegation of authority is inappropriate given that the imposition of restraints is not medical treatment, but rather an economic measure taken in order to ensure that the home's operation remains viable within the provincial funding mechanism. Since neither physicians nor registered nurses have any control over long-term care operating budgets, it stands to reason that the authority to impose restraints should rest with the party that *does*: the Ministry. This would relieve overstretched family physicians of a duty for which they have no enthusiasm. It would also relieve registered nurses of a conflict of interest, since the renewal of restraint orders provides an economic benefit to their employer - often a for-profit corporation.

Sixth, freedom has been discounted by the unwillingness of regulatory bodies to monitor the imposition of physical restraints on residents. The Ministry does not actively monitor the use of restraints in the homes, nor do either of the two regulatory colleges. Instead, the College of Physicians and Surgeons of Ontario and the College of Nurses rely on a complaint procedure to review the activity of individual physicians and registered nurses in the authorization/renewal of restraint orders. But since a "successful" complaint would invariably result in the resident being removed from the home by the operator (as an unrestrained safety risk), this is a most unsatisfactory way to regulate the use of restraints.

Given the unwillingness of the two colleges, and the Ministry, to monitor the use of restraint, it is safe to say that *no one knows* how many residents are currently being physically restrained in the homes - and no effort is being made to *find out*. Certainly in my discussions with Ministry officials and with the organizations representing the physicians, registered nurses and home operators, there was no sense of urgency in examining what was transpiring in the homes regarding the use of restraints.

This lack of interest was also apparent during the appearances by these organizations at committee hearings on Bill 140, *The Long Term Care Homes Act*,[1] in the spring of 2007. No concerns were raised about the use of restraints despite the fact the bill contained *no measurable improvement* for physically restrained residents.

Politicians have also shown a reluctance to engage in the restraint issue. For instance, opposition party health critics did not challenge the government on the restraint issue during the entire Bill 140 debate in the legislature - despite a series of very misleading statements made by the government as to the bill's supposed restraints provisions.

The absence of any meaningful discussion by politicians and long-term care organizations no doubt reflects the difficult nature of this subject matter. But it also suggests that substitute decision-makers of physically restrained dementia residents have not made the use of restraints a serious issue with elected officials or health care professionals.

This atmosphere of complacency is most unfortunate, given that there are practical ways to provide a *measurable improvement* for this group of residents, in terms of: reducing the number of restrained residents by providing them with a suitable physical environment; and reducing the time spent in restraints by ensuring regulated release.

On the first point, it would not require any additional funds to provide an environment that is properly outfitted and configured for use by ambulatory dementia residents. What it *would* require is a firm belief in the value of preserving their freedom, and a willingness to take the necessary steps - thereby setting aside any preconceptions as to what such an environment should look like.

Cosmetic applications need to be considered in the context of promoting mobility - and not the other way around, as seems to be the case at present.

On the second point, physically restrained residents must be given the opportunity of daily, regulated release from restraints - period. To shoulder the cost, existing Ontario Health Insurance Plan funding for twice-weekly physiotherapy visits could be redirected towards a more cost effective, daily, regulated assisted walking program, run by the staff of the home operator. Equipment such as a "walking jacket" could also be used as a cost effective means for substitute decision-makers and others to walk safely with unsteady residents during their visits to the home.

Despite these opportunities for *measurable improvements*, the value of preserving the freedom of dementia residents continues to be heavily discounted by current legislation and regulations, with no end in sight. To neutralize their affect, our family has found it necessary to establish a physical presence in the home in order to suspend the implementation of Ministry restraint policies, as they affect my mother. This freedom has provided her with a tremendous amount of satisfaction and enjoyment, as well as benefits to her physical health.

My mother's condition - stroke dementia - is not unusual. It would be extraordinary if, among all of the physically restrained dementia residents in the homes, she was unique in her aspiration for freedom. With that in mind, it is time for the Ministry, as system regulator, to expeditiously *quantify* and *qualify* the use of restraints in the homes. This information would lay the groundwork for the evaluation of reasonable alternatives to the imposition of physical restraints on dementia residents in the long-term cares homes of this province.

[*] George Parker is a substitute decision maker who has spent the past three years familiarizing himself with provincial restraints regulations, in order to better understand the situation his mother is facing in a long term care home in Cobourg, Ontario.

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[1] Both the parliamentary debates and submissions made to the Standing Committee on Social Policy can be viewed at: http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=464&isCurrent=false&detailPage=bills_detail_debates. Bill 140 has received Royal Assent but has not yet been proclaimed.

EMPOWERING PERSONS USING THE TIDAL MODEL

Lisa Murata* and Margaret Tansey**

Empowering Persons Using the Tidal Model

In 2001, nurses at the Royal Ottawa Hospital[1] adopted the Tidal Model as their model for practice. Professor Phil Barker developed the model in the United Kingdom in the mid-1990s in response to the question: What are psychiatric and mental health nurses needed for? The model has contributed to a change in nursing practice by increasing person-centeredness, collaboration, and by empowering persons-in-care.

Collaboration

Collaboration starts at admission with the Holistic Assessment. Nurses learn who the person is through the person's sharing of their story in their own words. The Holistic Assessment can be documented by the person in handwriting if they so chose. The nurse is respectful of the person's language. The person is offered copies of the story and asked to sign the documents that they co-create with their nurse. The documents then become part of the clinical information record. The nurse asks questions such as what happened to bring them to the hospital, how things had changed over time, how they feel now and what they would like the nursing staff to do to help them. Nurses inquire about the person's goals for their admission, who are the important people in their life and why, what is important to them and why, and what ideas about life are important. Persons also list their problems and describe how much their problems disturb them, distress them and how much control they feel they have over the problems using a scale from 0-10. From the admission, the person's story guides the nurse, the team and the person-in-care by describing their goals and what needs to happen for the person to be discharged.

A security assessment is completed should the person be at risk to self-harm, harm others, self-neglect, or suicide. The security assessment is a collaborative risk assessment. Included in the assessment is the person's scaling of their risk on a scale from 0-10. The nurse also rates the person's risk and if the numbers do not match the nurse explains the reason in a transparent fashion. The nurse and person create a Security Plan through answering what and who have been helpful in the past. All documentation is written in the person's words and signed by the person.

The daily care plan is also done collaboratively with the person. The plan is a personalized assessment of where the person is in relation to goals and what needs to happen next. Small steps are listed as the person's assignment for the day. The person chooses the assignment and the nurse may offer some input. The person signs the form, as does the nurse, and may choose to have a copy. The care plan includes any changes that have happened in the last 24 hours and what has worked. The nurse asks what the person did to make things work and what is planned as a next step in terms of reaching the overall goal.

Strength-based, Person-centered Care

Inherent in the model is the recognition that people are the experts in their own lives. They have coped with their problems up until now but may need some assistance at this time from the nurse and the interdisciplinary team. People ultimately know what is good for them.

The Ten Commitments

The value base of the Tidal Model is expressed in the Ten Commitments[2] which are congruent with person-centered mental health care that is respectful of culture. They are the essence of the Tidal Model and essential to practicing this model. The Ten Commitments are as follows:

> ***Value the voice***: the person's story is the beginning and endpoint of the whole helping encounter. The person's story embraces not only the account of the person's distress, but also the hope for its resolution. This is the voice of experience. We need to guard it well, as the voice begins to help the person to make her or himself anew. For this simple, yet powerful, reason we emphasise that the story of the recovery voyage - and all the care plans supporting it - should be written in the person's own voice.
>
> ***Respect the language***: the person has developed a unique way of expressing the life story, of representing to others that which the person alone can know. The language of the story – complete with its unusual grammar and personal metaphors – is the ideal medium for lighting the way. There is no need to colonise the person's story - substituting the often arcane, ugly and awkward language of psychiatry, psychobabble or the social sciences. People already own the most powerful language for describing, defining and articulating their personal experience - their own language.
>
> ***Develop genuine curiosity***: the person is writing a life story but should not be confused with a 'open

book.' Those who seek to be of assistance to the person need to develop ways of expressing genuine interest in the story – as written and as it continues to be written - so that they might better understand the storyteller and the human significance of the unfolding story of their life.

Become the apprentice: the person is the world expert on the life story. We can begin to learn something of the power of that story, but only if we apply ourselves diligently and respectfully to the task by becoming the apprentice.

Reveal personal wisdom: the person has developed a powerful storehouse of wisdom in the writing of the life story. One of the key tasks for the helper is to assist in revealing that wisdom, which will be used to sustain the person and to guide the journey of reclamation and recovery.

Be Transparent: both the person and the professional embody the opportunity to become a team. If this relationship is to prosper, both must be willing to let the other into their confidence. The professional helper is in a privileged position and should model this confidence building by being transparent at all times, helping the person understand what is being done and why.

Use the available toolkit: the person's story contains numerous examples of 'what has worked' or 'what might work' for this person. These represent the main tools that need to be used to unlock or build the story of recovery.

Craft the step beyond: the helper and the person work together to construct an appreciation of what needs to be done 'now.' The first step is the crucial step, revealing the power of change and pointing towards the ultimate goal of recovery.

Give the gift of time: there is nothing more valuable than the time the helper and the person spend together. Time is the midwife of change. There is no value in asking 'how much time do we have'? We have all the time there is. The question is, surely, how do we use this time?

Know that change is constant: The Tidal Model assumes that change is inevitable since change is constant. This is the common story for all people. The task of the professional helper is to develop awareness of how that change is happening, and how that knowledge might be used to steer the person out of danger and distress back on to the course of reclamation and recovery.

Evaluation Studies

Two prior evaluation studies completed in Newcastle[3] demonstrate decreases in lengths of stay, self-harm, violence, aggression, use of restraints, and enhanced participation in care when using the Tidal Model. At the Royal Ottawa Hospital, a similar evaluation study was replicated to assess outcomes. In the three programs where the model was first introduced, measures were taken before the introduction of the model and over three yearly, three month intervals. The numbers of risk incidents were too low for analysis statistically but a decreasing trend was found. Significant increases were found in the number of documented verbatim quotes demonstrating increased participation of persons-in-care.

The decision to practice using the Tidal Model has been beneficial to nurses and persons-in-care. It has resulted in increased collaboration and empowerment. The person feels they are being listened to and that what they say matters. Nurses approach persons in a respectful way, recognizing the person's strengths and resources. Nurses are no longer advice-giving experts. The person's expertise in their own life is drawn upon to reach the person's goals. One person on the inpatient Mood Disorders Unit commented about the Tidal Model:

It makes it easier… because it gives some structure to work with. It helps us focus when we have difficulty focusing. It helps you understand when we have difficulty because it is very specific so it allows you to see in our words how we are feeling and what we want, and need. I found it helpful over the years because it allows the nurse to understand where we are coming from, and allows us to understand and makes us think of things. It helps to see the change, the progress from the beginning to the end of our stay.

Nurses have had to learn to practice in a different way. It has been a steep learning curve at times but meaningful change has occurred for both the staff and the persons-in-care.

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1 The Royal Ottawa Mental Health Centre is a 197 bed mental health facility providing tertiary care to the population of the Champlain district in Eastern Ontario.

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3 Fletcher, E., & Stevenson, C. (2001). Launching the tidal model in an adult mental health programme. *Nursing Standard, 15*(49), 33-36; Stevenson, C., Barker, P., & Fletcher, E. (2002). Judgement days: Developing an evaluation for an innovative nursing model. *Journal of Psychiatric and Mental Health Nursing, 9*, 271-276.

PHYSICAL RESTRAINT IN ONTARIO – MOVING FROM "RESTRAINTS WITHOUT DEATH" TO "LIFE WITHOUT RESTRAINTS"

Bruce Kappel,[*] Joel MacIntyre[**] and Gail Hurren Jones[†]

Between 1988 and 1995, the Office of the Chief Coroner for Ontario investigated 21 unexpected deaths involving the use of restraints. In 2000, a survey of 355 Ontario care facilities for children and adults indicated that 80% of them used physical restraints. Over 95% of the facilities for children with mental health and children or adults with developmental disabilities reported using restraints.[1]

In schools, family homes, and residential services across Ontario, people with intellectual disabilities and people with mental health issues are being physically restrained. In the past, restraint was seen as a treatment option, but today the rationale is primarily one of protecting people – the person being restrained, the people sharing their living or learning space, and the staff who support them.

Protection may be the goal, but experience and research indicate that the use of restraints does harm. It is a traumatic event that has far ranging impacts on those who are restrained, those who do the restraining and those who witness it. The use of restraints represents a failure in the supports provided to people. Where supports are responsive to the needs of the individual, restraints are not needed. Restraint use is not therapeutic. Many people who are restrained have a history of trauma, and the use of restraints is yet another trauma. Post-traumatic stress disorder is seen as an outcome of restraint use.

We are at a crossroads in our collective approach to the use of restraints in human services. One road supported by current provincial policy appears to be ensuring that the use of restraints does not cause death ("restraints without death"). Another road is to collectively dedicate ourselves to ensuring that restraints are neither needed nor used ("life without restraints").

A Tale of Two Lives

On February 21, 1994 James MacIntyre's name was added to the growing roll of those who died because they were restrained – William Edgar, Stephanie Jobin, Robert "Tex" Gentles, and Lau Szeto.

Jim was staying in a men's hostel in downtown Toronto. He was involved in an altercation. A number of staff took him down and restrained him on the floor. He stopped breathing and died in hospital. The cause of death was determined to be hypoxic ischemic encephalopathy following cardiac arrest. According to the coroner's jury, the means of death was homicide. The men who caused Jim's death did not even know his name.

Jim's family and circle of friends pushed for a coroner's inquest. They advocated for a number of systemic changes, including: efforts to promote the full social inclusion of people who are homeless and experience mental illness; the development of citizen advocacy programs; a commitment to integrated and supportive housing; and a culture that allows for "places of hospitality" and true sanctuary rather than warehousing. While the coroner's jury supported some of these recommendations, and made many others, little of substance emerged.

One change did emerge, however, in the context of other deaths. In 2001, John Baird, then Minister of Community and Social Services (MCSS), declared: "Our goal is to have a world where physical restraints are not necessary. However, until we reach that point, we must be clear on how they can be used."[2] This led to tighter definitions on when restraints can be used, as well as mandatory training and reporting.

Unfortunately, there has been no monitoring of the progress made towards the goal of a world where physical restraints are not necessary, and no indication of a real policy commitment to that goal. To date, MCSS has neither collected nor analyzed the data on restraint use in developmental services. Calls for the MCSS, as well as the Ministry of Children and Youth, and the Ministry of Education to develop strategies to move toward the goal have gone unheeded.

Throughout the province, there are compelling stories of efforts to eliminate the need for physical restraint use and alternative strategies. One of those stories started about the same time Jim MacIntyre was murdered.

At that time, Martin (a pseudonym) was a boy with autism living at home with his family. His family was having a very hard time controlling his behaviour, which included strong aggression toward others and hurting himself. The family sought the help of professionals. Those professionals prescribed an approach involving very aggressive, if not abusive, behaviour management. From 9 a.m. to 5 p.m., it was the job of two staff persons to control Martin. If he threw food on the floor and attempted to eat it, they were instructed to throw the food away and give Martin nothing more to eat. At 5 p.m., Martin was restrained – tied at his wrists and ankles to a hospital bed in the basement. He stayed in those restraints until staff returned the next morning. Not surprisingly, as a result of this approach, Martin lost some of the skills he had when he was younger.

Martin's family recognized the harm of this approach to both Martin and the family as a whole. They were in crisis and looked for alternatives. At the local planning table, one agency stepped forward. It had a "vacancy" in one of its group homes. It welcomed Martin, but not his bed and not his restraints. The psychologist involved with the agency and a team of staff dedicated to a different approach tried to pay attention to what Martin had to say by his behaviour. The senior manager committed the team to building a relationship that would not fall apart because it was too tough. They gave Martin the space he needed. He was not forced to follow group routines and schedules. Within a month he was eating at table, not off the floor. Within several months, he was eating at table with others. He went back to school. Many approaches were tried and many were successful. They involved giving Martin lots of space and options so he was far less anxious. Only staff that connected with Martin were assigned to support him. He lives in a house with a "no restraint" policy. He now has his own apartment downstairs in the group home. He visits his family often and they are quite involved in his life.

Try Another Way

Morally and ethically, we must find a way to support people well in community and "do no harm" in the process. Our services must provide sanctuary and healing, not control and trauma.

Across North America, there are growing efforts to radically reduce and eliminate restraint use in human services. These efforts are often informed by the following three considerations:

- Focussing on the "appropriate use of restraints" or "the use of appropriate restraints" may increase, rather than reduce, the use of restraints as caregivers feel more capable and secure. Minimally, it focuses responsibility on front line staff to redirect, rather than the entire agency to find better ways to support people without causing trauma.
- When the policy goal is to develop restraint free environments, and resources are dedicated to reaching that goal, there is much greater emphasis on developing environments and ways to support people that appropriately address the issues in their lives.
- There are approaches which support people with challenging behaviours that do not involve the use of restraints. They often require a cultural shift in human service organizations, not just add-on training.

There is some anecdotal evidence to suggest that the use of restraints has decreased dramatically in some settings in Ontario. One agency provided restraint training to its staff long before MCSS required it. In some service clusters within that agency, restraint use continues. Staff are trained in the techniques, and they are used while within another cluster, there is a commitment to eliminate restraint use by developing more effective support strategies. That cluster does not refuse to support more challenging people, and does dedicate itself to finding better ways to do so. Staff are still trained in restraints use, but there is far less need to use them. The commitment to different approaches has moved from the level of individual staff trying to redirect behaviour to a cluster-wide commitment to developing strategies that work. Other agencies have instituted straightforward "no restraints" policies. Unfortunately, they are still required to train staff in restraint use.

In other words, where there is a commitment in policy and practice to what John Baird said in 2001, real change happens.

We must do better in Ontario. The major emphasis has been on training staff, and even then only staff in certain sectors. The training is individually focussed – to respond differently to avoid the use of restraint and to do so safely when they do restrain someone. There is no fundamental encouragement to develop approaches that eliminate the possibility of using restraints. There is no commitment to systematically determine if the measures instituted so far have actually worked. The approaches taken by various Ministries are inconsistent.

A group of citizens, people with disabilities and professionals came together out of the MacIntyre family's efforts to make a real difference. *Citizens Against Restraint* is working to raise awareness about the true and traumatic impact of human service restraint use. We want to stimulate discussion about the moral issues involved, the kind of society we want to live in, and what that society does in our name. We want an end to government approval and funding of restraints use. We want more relevant and effective moral approaches to serving vulnerable people adopted and supported. For more information, you are invited to visit our web site – http://www.citizensagainstrestraint.org/car/car.htm.

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The authors have numerous organizational and professional affiliations, but write from their personal connections to people who have been restrained and their efforts to effect change.

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HONOURING THE PAST, SHAPING THE FUTURE: FAMILY MENTAL HEALTH CARE

Tunde Szathmary[*]

The Family Mental Health Alliance (FMHA) is pleased to have the opportunity to contribute to the Psychiatric Patient Advocate Office's (PPAO) 25th anniversary collection of reflections on progress in mental health and advocacy. We are a network of family organizations and individual family members giving a voice to families' issues in the mental health system, and raising awareness of a family perspective. In short, we are advocates for families and family support organizations. We understand something of the passion for justice, a "level playing field" and the empathy that drives advocates. Our commitment is not only to families and friends coping with the mental health problem of people they care about, but also to those very people they care for. They are members of our families and our friends.

Pre-1970s

It is impossible to appreciate the developments of the last 25 years without knowing what went before.[1, 2] Centuries ago, there were no alternatives to family mental health care. Families coped with challenges as best they could, guided by cultural precepts, demands of life and whatever resources were available to them. It is commonly held that ill family members were treated deplorably but some research suggests otherwise. Modern fieldwork in the third world has shown that people living on the edge of self-sufficiency need every helping hand. Relatives with illness could still make an important contribution and seemed to do better than those in advanced nations. This scenario likely reflects the distant past, not only from a utilitarian perspective but also from the fact that it is unreasonable to think families of yesteryear had any less family love than families do today.

The negative stories about family care mostly derive from the development of asylums. History has it that the inspiration for asylums was generous: to provide a safe haven from jails and poorhouses, and from communities and especially families that had failed in care. The truth is that many asylum inmates were immigrants without family to support them. Among those with family, urbanization and industrialization played a greater role than family wishes in incarceration. Male breadwinners could not absent themselves from paying work to accommodate the needs of disabled wives around household tasks and children. They could not be close-by to deal with external situations that impinged on the vulnerabilities of their wives. Destitute wives with ill husbands could not easily access charitable supports for the family unless they were deemed worthy as single parents abandoned by their men. Even under these pressures only the most serious and persistently ill patients were admitted.

Families without access were left to manage as before, without assistance or interference, provided they met their social obligations for self-reliance. No doubt some families took extreme measures, yet all families bear the brunt of stories of neglect and cruelty. This public image was reinforced in the 20th century by new theories such as psychoanalysis, which attributed mental breakdowns to parental, particularly maternal, dysfunction. Families were derelict in their duty to care if they did not accept responsibility and try to obtain support for their relatives. As a result, the government was under pressure to increase beds in asylums, renamed provincial psychiatric hospitals (PPHs). As the number of beds grew, governments were also forced to reduce public dependence through a search for remedies, a cause shared equally with service providers and families, albeit for different reasons.

Experimental treatments of every sort from opiates, lobotomies, insulin shock, electroconvulsive therapy, hallucinogens and pharmaceuticals were tried with varying impacts on mental health status. There are two ways of looking at this period today. The positive approach is to recognize that some treatments seemed successful and raised the hope that advances would help people resume their lives in the community. The counterargument focuses on the suffering of people who were human guinea pigs and left to live with negative results. Many people suffered grievous harm on top of institutionalization. Some of this controversy survives today and requires greater efforts at reconciliation of consumer/survivors and mental health care system supporters to cohere as a community for mental health care advocacy. At the time, however, the former approach held sway with government because it enabled deinstitutionalization.

Family ties were typically broken when a relative was admitted. The weight of years of absence, no less than service provider advice to move on, meant that there were almost no families to welcome discharged relatives home. Families that had insisted on maintaining contact, usually as a result of financial means and community status, were hardly prepared to cope with loved ones profoundly changed by their illness, the traumas related to it and/or care and treatment, let alone ongoing challenges. Emerging community mental health agencies were equally unable to cope with the demand for support. Families and PPHs advocated for retention of psychiatric beds while community agencies advocated for transfer of institutional resources to community care.

Canadian Medicare added to the stew.[3] Pre-existing provincial health care programs such as PPHs were not eligible for cost-sharing, in contrast to psychiatric wards in general hospitals (GH) and community psychiatry. The demand for GH psychiatric care increased, not only from former PPH patients who had relapsed, but also from the opening up of care to the broader community. People with serious but not persistent or less serious but persistent mental health problems could now hope to secure professional help. Certainly the families that had hitherto provided care hoped so, as did families facing emerging illness – not yet serious or persistent but worrisome nonetheless.

While PPHs were in decline, providers there observed the phenomenon of the "revolving door." Discharged patients were cycling through readmission and discharge again and again. Some were said to have come back for the necessities of life: a roof; meals; and the only friends they knew. Others broke down for various reasons besides medication non-compliance. Medication alone did not ensure mental health recovery. The demand for care in serious mental illness was very great and GHs were accused of accommodating the "worried well."

A Paradigm Shift

The mental health care system was in disarray with community agencies, PPHs, GHs and families competing against each other with regards to what was necessary in mental health care. By the late 1970s and early 1980s, family support groups were established to help family caregivers and friends help themselves and each other. While individuals continued to advocate on behalf of a loved one, some groups actively assisted them in improving their prospects for individual system supports. Most groups also recognized the common thread in family concerns as matters for more organized advocacy not only on service and support improvements for people with mental illness in general, but also for families and friends who undertook basic homecare in an increasingly community-based mental health care environment.

The paradigm shift came with the Graham Report, *Building Community Supports for People*[4] in 1988. In unmatched conciseness, the Ontario Community Mental Health Committee recommended that the government recognize that 11 essential elements were necessary for an effective mental health care system and that it must plan for such a comprehensive system in partnership with service providers, consumers and families. The essential elements were really functions that any system should be capable of expressing: identification; crisis and treatment; case management; coordination; housing; vocational supports; social supports; peer supports; family supports; and advocacy. The family sector was jubilant that their caregiving was recognized to the extent that family supports were deemed essential in effective mental health care.

One of the Graham Report's most valuable but underappreciated ideas was the concept of "functional equivalence." It meant that the provision of support could come from a variety of channels. If families could not come together in groups, as might be the case in rural areas or with language barriers, family support could still be provided by alternate means such as a relative's case manager or doctor. It did not seem far-fetched to expect service providers to try to support the families they often depended on to provide community care for their clients. This was an inspiring vision for families.

An amazing process began across Ontario where service providers, consumers and families sat down to conceptualize one mental health care system that served their common needs and interests. Participants in these collaborations were energized by the discovery that sharing their perspectives need not be divisive. Mutual understanding could bridge differences and create consensus on the kind of community care everyone wanted.

In the early 1990s, the government took the next step by allocating new money for a limited number key supports that seemed to be consistently prioritized in local planning across the province: crisis services; case management; housing; and consumer peer and family supports. For families it was an empowering time. Not only were supports for them funded as a formal part of the mental health care system, but the Ministry of Health and Long-Term Care's guiding policy required family involvement in system planning, evaluation and services and supports representation. Family representation quotas (20%) were required for a new round of District Health Council led implementation planning.[5]

Retreat

A decade is a long time to plan, especially since there were issues put off to the future. The Graham Report recommended a concerted focus on people who had serious mental health problems. While a triage system made sense because of the closure of PPH beds, it nevertheless set unwelcome limits on mental health care not faced by other diseases covered by Medicare.

For families, the categorization of seriousness was very much influenced by their lived experience as caregivers. It did not sit well when a loved one talked of suicide but was not admitted because he or she was "merely" depressed and/or seemed lucid and in control by their service provider through the very fact of seeking help. Families and friends who observed very limited capacity in the activities of daily living such as loved ones with agoraphobia or other phobias and/or compulsions, were not content with prioritization of access to services the basis of psychosis or a diagnosis of a "major" mental illness. Families and friends experiencing episodes of extreme behavior in mood disorders worried about complacency with respect to intermittent illness in light of preferential access and service for people with on-going problems. Many families wondered why an illness had to become severe to obtain service.

All stakeholders recognized that there was a continuum of mental health problems and it was wrong to require that an illness reached crisis level before receiving attention. It was all the more wrong when research started showing that every full-blown breakdown increased the odds against complete recovery. Reform planning clearly represented the first phase of an incremental process of investments and change that would play out over many years. It couldn't happen soon enough.

Family patience was stretched because their relatives needed optimal care now – not at some future date. Their own problems in substituting for the system were overwhelming as well. While family groups provided a measure of relief through education and social support, the fundamental burden remained. Family groups were not resourced to respond to comprehensively, let alone innovate on their own or in partnership with other stakeholders. They were small in number and mostly volunteer-staffed. Families outside the "mainstream" with respect to language, racial or cultural identities, rural location and so on were still "alone."

These problems mounted as mental health reform seemed to come to a standstill. More planning was assigned to a number of task forces restricted in communications with local stakeholders except in invitation-only consultations. The grassroots in family mental health care advocacy was starved for news on reform while additional issues were arising. Attention was turned to the government's hospital restructuring. The extensive mental health planning undertaken to date seemed to have little impact on decisions regarding a critical resource in mental health care. In Toronto, for example, the hospitals to be closed had in recent years attempted to develop their own niches in the system, including among other initiatives, expansion of mental health beds. In contrast, the winners in restructuring had all been closing mental health beds.

As worrisome were other changes in government support, such as: the end of government involvement in housing; changes in eligibility and levels of disability supports; enhanced capacity for removal of children and adoption by Children's Aid Societies; and so on. Each of these issues and others required advocacy from family sector. Aging parents could not guarantee life-long shelter. Neither they nor siblings or adult children could easily complement destitution level income supports, which were even lower if the family could have the relative live at home. Families risked loss of grand-children, nieces and nephews along with the recognition of the searing pain this causes for ill relatives they love. There were challenges everywhere and hardly enough space for advocacy given the primary focus of family support groups and programs on helping families cope.

This was the environment in which the Family Mental Health Alliance was born although discussions on the mutual benefit of family sector collaboration started years before. There was a clear need for a voice for families. The FMHA's intention was to take on a role that challenged the resources of family support groups and programs, not to redirect their attention or compete with them for volunteers necessary for direct service to families. Its success over the years, let alone survival, owes a lot to its core of members committed to systemic issues and the awesome support of families by public bodies.

The family sector was grateful to have general recognition of their increasingly difficult burdens by the Romanow Commission[6] and then by the Kirby-Keon Senate Sub-Committee.[7,8] Even Health Canada undertook a survey of mental health family caregivers and documented their hardship in measurable terms of hours and money.[9] It is very hard to document the more ineffable experiences of family care-giving.

There was great hope that reform would eventually get back on track with a new government under the party that had initiated the work of the Graham Committee. The government decided instead on another major transformation. It undertook regionalization through the establishment of locally appointed boards, Local Health Integration Networks (LHINs), with the defined purpose of integration of all health services within their area.

Integration sounds like a good idea given all the evidence of silos of care. Even the Graham Report noted the problems of fragmentation and counted co-ordination among its essential elements. There were concerns, however, that integration was merely a code word for forced mergers and amalgamations as carried out previously by the Health Services Restructuring Committee with regards to hospitals. LHINs have the authority to close down an organization altogether. Many programs and organizations, including family groups, had developed precisely because there was an unmet need that required specific attention. They were fully embedded in their respective constituencies and developing expertise in meeting identified needs. To suggest that an external body could simply transfer ownership to another organization that had not or could not meet such needs before was overwhelming in its audacity. In the worst case scenario, their meager funding could be pulled, leaving their service capacity to evaporate. Volunteers would carry on but nobody knew for how long before they burned out. Would anything of the organization's acquired knowledge pass on or would it need to be "rediscovered" again by the new provider? How was that efficient?

Local determination also sounds good, but it was difficult to envisage among those who had been involved in mental health reform. They knew of the wide disparity in service availability across the province and the amount of resourcing that was identified under reform that had yet to be invested. There was real concern about the creation of a patchwork of mental health care systems where one's location determined the nature of access and care. How could details like Graham's essential elements of effective mental health care or even "functional equivalence" get a hearing when every other publicly supported health care program got thrown into the pot of services to be resolved locally and funded wholly by whatever allocation the government determined to give?

The absolute worst thing for families, however, was the government's neglect to include family caregivers as legitimate stakeholders in the proposed legislation, and then reject amendments that would have brought them in. In one stroke, the government undid 18 years of partnership with mental health families.

The Future

It is difficult now to feel the same confidence that families had under mental health reform. From 1989 through to 2006, all stakeholders were mutually responsible for and to each other. Now there is no requirement for responsibility to and for families. Yet the system can continue to capitalize on the love and care families provide.

The one reason for hope is the consensus derived from those optimistic reform years. Families are appreciated by their sector colleagues. The FMHA has partners who support the voice and involvement of families and friends. With them, the FMHA developed a family-focused paper making recommendations, such as: enhancing services and supports to families, including supporting family peer support and family organizations; involving families as partners in care, rehabilitation and recovery; and including families as system partners.[10]

Families were, are and will remain an essential element in effective mental health care. However, it is not enough for our partners to speak on our behalf. They have enough of their own issues to bring forward without having to second guess ours. It's not enough to add the words "and families" to realistically expect an ability to zero in on the details of need and support that only families themselves can flesh out. Families must continue to be at the table not only for the well-being of family caregivers, and the friends and relatives they support, but for the sustainability of an increasingly community-based public health care system in which everyone has a stake.

Family advocacy will continue not only because of the FMHA's particular advocacy for compassion, commitment and caring for families but also because in the real world, service providers, consumers/survivors and families are truly co-producers of effective mental health care. This systemic interdependence means that the ethical duty to care applies across the board: from consumers at the centre and in waves outward to encompass everyone who cares for and about consumers. We must all stand together in mutual support to enable best outcomes and recovery from mental illness.

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FAMILIES AS ADVOCATES IN THE MENTAL HEALTH SECTOR

Ursula Lipski[*] and Deborah Deacon[**]

Over the past several decades, care for people with severe mental illnesses has shifted from being primarily institutionally to community based. Deinstitutionalization and the resulting emphasis on community care have increased demands and expectations for families to provide care and support for their relatives with mental illnesses. As has been seen with shifts to community and home care in all health care sectors, not just mental health, family members have been called upon to provide a wide range of services and supports that were formerly provided by institutions.

As the mental health system has become more reliant on families, its view of families and their roles and impact within the mental health system, has changed as well. When the Schizophrenia Society of Ontario was founded almost thirty years ago, family members, particularly mothers, were often being blamed by mental health professionals for causing or exacerbating schizophrenia. As our understanding of the causes and treatment of mental illnesses has evolved, so too has our understanding of the role of families.

Family members are often the core supports for people with mental illnesses, being involved in virtually all aspects of treatment, care and recovery. Families may provide housing, financial assistance, social and emotional support, and help with day-to-day living. Family members often describe themselves as the case managers, crisis workers, or system navigator, helping people access treatment and support services as required. A common tenet of all these roles is that of advocate. Because family members are often so intensely engaged in these caring and support roles, they bring unique perspectives and voices to discussions around mental health reform and service improvement.

Families as Advocates

The role of families as advocates in the mental health sector is dynamic, evolving and paralleling an individual's movement through various stages of mental illness and various levels of service. This dynamic advocate role can be loosely described as emanating from a central core akin to the individual level and moving out to the community and ultimately to the system levels. Although families may progressively move to advocating for change at different levels, the core or the raison d'être of their advocacy efforts remains the individual. Figure 1 illustrates these emanating advocacy levels in which the individual remains central.

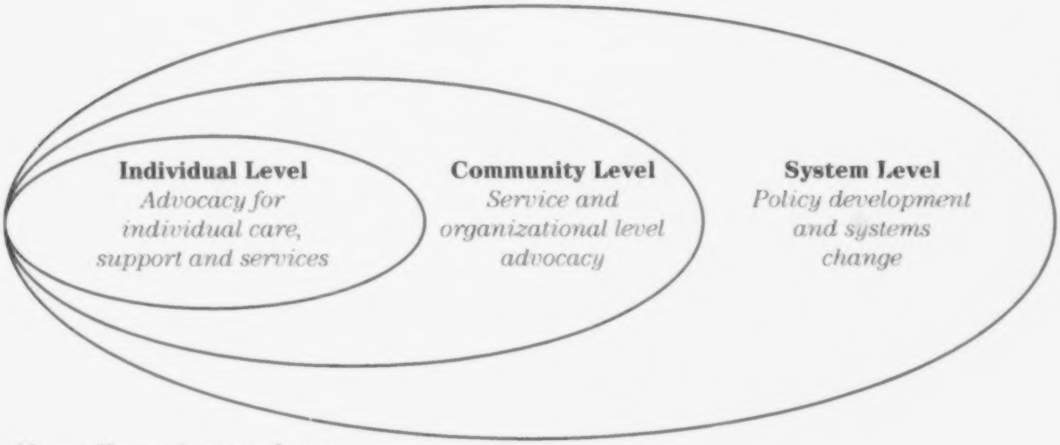
Individual Level
Advocacy for individual care, support and services
Community Level
Service and organizational level advocacy
System Level
Policy development and systems change

FIGURE 1 - MENTAL HEALTH ADVOCACY LEVELS

Individual Level Advocates

When a family first suspects that mental illness may be involved, or when they first receive a diagnosis of mental illness, they may be in a state of shock or disbelief, and at a loss as to how to get help for their family member. Unlike other medical or physical illnesses, there is generally no clear pathway to accessing mental health care. Do you go to the emergency department, the family doctor, a local health clinic, the police department, or a psychiatrist? Despite efforts to improve access to psychiatric care, access remains a critical issue for people with mental illness and for families. Access is particularly challenging in cases where an individual may be clearly ill and in distress, but is not willing to seek voluntary treatment.

Whether families are trying to access care through voluntary or if necessary, involuntary means, their primary concern is ensuring the individual well-being of their ill family member. They may focus on accessing mental health care (in-patient or out-patient), or getting the best possible psychiatric specialist, or the right mix of medications, or the right therapy. At this stage, families are advocates for care with the hope that their relative will access the treatment and supports they need for recovery.

Community Level Advocates

As a person with mental illness moves through their recovery process their needs change, and with this change comes a corresponding shift in the role of families. For instance, people may need to access a host of community services and supports to help sustain their recovery. They may be in need of housing, a social support program, community services such as those of assertive community treatment teams, employment supports or enrolment in the Ontario Disability Support Program. Often, it is the family that helps the individual navigate the web of services and supports, and subsequently apply to the appropriate services. At this stage, the family is advocating for community resources and services that will help their relative continue to stay well. Families may participate on boards or planning committees of local service providers with the view to ensuring organizations provide the best possible care to their family member and to other service recipients as well. Although the family advocate role is now targeted at community level organizations and services, the primary motivation or purpose of the advocacy remains the well being of individuals with mental illnesses.

System Level Advocates

Some families are not satisfied with individual or community level advocacy, but desire to advocate for systems, policy and legislative change to improve the overall mental health system or the broader social welfare system. For instance, families in Ontario were very instrumental in advocating for changes to the Mental Health Act in 2000 which introduced community treatment orders and which made it easier to involuntarily admit someone to hospital if there was a possible risk to self or others. Families have also been calling for system level changes to ensure that people with mental illnesses have access to basic needs such as adequate incomes and housing. For instance, families have been actively advocating for increases to the Ontario Disability Support Program. As well families have been calling for improvements to the overall health system and have been demanding to be included as stakeholders in policy planning tables such as those of the newly formed Local Health Integration Network (LHINs).

As with the individual and community levels of advocacy, individuals remain the ultimate beneficiaries of these advocacy efforts. Although the ultimate goal is to improve the overall system, it is generally with the view to improving the quality of life of people with mental illnesses.

Opportunities for Families as Advocates

Over the last ten years, families have been increasingly recognized as important stakeholders in the mental health system. The Canadian Clinical Practice Guidelines for the Treatment of Schizophrenia, first developed in 1998, and subsequently revised in 2005, acknowledged the important role families play in the treatment, care and recovery of people with schizophrenia. The Guidelines also stressed the importance of the professional-family relationship and of the need to involve families in the treatment plans of their clients when appropriate. In 1999, the Ontario government's Making it Happen report, recognized family self-help groups as "resources in the planning, evaluation and governance of care delivery." Similarly, the Program Policy Framework for Early Intervention in Psychosis developed by the Ontario Ministry of Health and Long-Term Care in 2004 included family education and support as one component of comprehensive treatment for early psychosis. At the national level, reports of both the Romanow Commission and the follow-up report by Senators Kirby and Keon, also highlighted the importance of families in the mental health sector, and acknowledged the tremendous impact that mental illness has on families.

Despite this policy recognition, families and the organizations that support them, have continued to remain on the margins of the mental health system - struggling to access care and support services and struggling to be included around mental health policy tables.

This continuing marginalization led family advocates to bring together leaders in the mental health sector to collaborate in the production of Caring Together: Families as Partners in the Mental Health and Addiction System. This policy blueprint targets the provincial government, the Local Health Integration Networks (LHINs), and mental health service providers and makes the case for how and why to involve and support families in the mental health system. Caring Together calls on decision-makers to recognize and support families by:

- Enhancing services and support to families;
- Supporting family peer support and family organizations;
- Involving families as partners in care, rehabilitation and recovery; and
- Involving families as system partners.

Caring Together sets out a comprehensive policy framework that families and family organizations can build upon in their roles as advocates. At the systems level, the introduction of the LHINs, provides families with local opportunities for engaging in mental health policy decisions. With the LHINs mandate to engage the community in health care decision making, families and family organizations can challenge the LHINs to ensure the family voice is included in decision-making forums. This is a unique opportunity which families must seize.

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THE PRESENCE OF ABSENCE: UNDERSTANDING THE EXPERIENCES OF BEREAVEMENT IN LONG-TERM SURVIVORS OF MULTIPLE AIDS-RELATED LOSSES

Yvette Perreault*

An estimated 61,000 people are currently living with HIV/AIDS in Canada. Ontario has over 26,000 HIV positive test reports. Close to 15,000 Canadians have already died of AIDS. Over 8,000 of those were citizens of Ontario.[1] With each AIDS-related death, an extensive network of family, friends, colleagues, neighbours and health care providers are left behind to grapple with the loss. This article examines one facet of the human experience of HIV/AIDS: the bereavement experiences of HIV-infected and HIV-affected loss survivors within an AIDS-impacted community in Ontario.

A recent study sponsored by the AIDS Bereavement Project of Ontario[2] conducted in-depth interviews with 27 AIDS bereaved individuals to arrive at a description of the complex dimensions of AIDS-related multiple losses.

One of the participants was "DJ," a 40-year-old gay man who reported losing 110 "friends and intimates" and "an entire community and the life I expected to have." His experience mirrors that of other individuals who live at the heart of an AIDS-ravaged community.

> *"Dying is easy; it's living that scares me to death," says DJ. "I never experienced death until AIDS came along. My family of origin was intact at that time and the notion of death was far removed from my experiences. AIDS created a great deal of conflict for me within my family because at a relatively young age (25), I began to experience the loss of my social supports – an experience that even my parents hadn't begun to have. I didn't feel that I could talk about this with my family; I felt a stigma because it was AIDS.*
>
> *I do sometimes wish that I could react with tears and just have a good cry, but my emotions are largely clouded by anger. Death doesn't make me sad, it makes me angry; sadness to me suggests some sense of helplessness – which I don't believe is the response that this disease requires.*
>
> *What does seem to help my grief is getting involved – moving toward the problem rather than running away from it. I've moved closer and closer to the epidemic and got involved as an employee and volunteer in the community response to HIV/AIDS. Working on the issues gave me a sense of control (however falsely) and made me feel like I was an active participant rather than a passive participant in what would be the single most defining aspect of my life. But obviously, that same involvement that helped me cope also drew me nearer to more, and more frequent, death.*
>
> *Within this movement is also where I met the people who would become my strongest supports. You really don't understand the impact that AIDS has if you haven't been involved or affected. People who understand what I've been through understand my anger and know how to manage it.*
>
> *Overall, I think the biggest issue I deal with is this seemingly random selection of who got to die and who got to live. Early on we were all unaware of HIV and its threat; we were all interacting socially and sexually – and somehow some of us got infected and some of us didn't. My grief now comes through a lens of guilt – I am no better a person, no more valuable, my contributions to the planet will be no more significant that those who died. Yet I remain here, hugely grateful and hugely guilty."*

The Dimensions of AIDS-related Bereavement

These loss survivors reported experiences of traumatic, multiple loss that resulted in bereavement overload.[3] Bereavement responses manifested at all levels of human experience: physical; mental; emotional; spiritual; and social.[4] The six dimensions of AIDS bereavement arising from this study's findings are: confrontation with death; loss of the assumptive world; survivor syndrome; identity and belonging; making meaning; and rebuilding community. Notable is the notion of community life as it shapes identity and belonging; it is an essential component in creating meaning from traumatic events. Just as the participants described the impact of loss at the individual and community levels, so too did they describe the necessity of community in reshaping a personal sense of an assumptive world.

Categories	Key questions	Themes
Confrontation with death	• "They're all dying. . . . What is happening?"	• Current loss triggers old loss • Traumatic impact of numbers and kinds of deaths • Stress of societal stigma • Disenfranchised grief • Grief overload; no time to grieve • Intense emotional, physical, spiritual, mental reactions
Loss of the assumptive world	• "So much is lost. My world is dying. . . . What does that mean for me?"	• Losses are more than the deaths of people • Losing a community that was mourning a life that never will be • Deaths of people who formed 'community of meaning' • Sources of support not available as friends/families die • Stigma and lack of societal support become additional losses
Survivor syndrome	• "But I'm still here. . . . Why am I still here?"	• Randomness of infections and deaths bewildering • More than feelings of 'guilt': anxiety, rage, confusion • Lack of language to convey experience • Lack of entitlement to grieve or to feel joy • Coping: choices to be made — withdraw or get involved • AIDS activism as response
Identity and belonging	• "Who am I now?" • "Where do I belong?"	• Role of culture and pre-AIDS community as reference • Paradox of belonging and becoming involved: sense of control but closer to death and pain • Longing for intimacy and authentic connection Identity disruptions caused by HIV/AIDS; distinctions emerge based on HIV sero-status • Sero-status distinctions impact sexual and intimate relationships • Long-term survivor identity emerges
Making meaning	• "I have to find ways to make sense of the non-sense." • "Who am I becoming?"	• Transformation: shaped by death, loss and survival • Paradox: living with ambiguity • Anguish of invisibility and meaninglessness • Resiliency, future • Values of love, tenderness, compassion, 'generosity of spirit' • Community engagement: social justice agenda furthered • Legacy work: remembering the past; honouring the dead
Rebuilding community	• "Is this is the new normal?" • "What is left?" • "Who else is here with me?" • "What now seems possible?"	• Living with uncertainty and ambiguity: AIDS isn't over • Concerns for the next generation • Challenges of attaching, reinvesting and transforming • Deeper resolution of grief contributes to individual and community health • Work remains on larger social justice issues: poverty, racism, sexism, homophobia, violence • Desire to dismantle the barriers between survivors; find allies and role models • HIV$^+$ and HIV$^-$ desire active role in task of rebuilding common identity: HIV$^+$ and HIV$^-$: 'we are all bereaved'

TABLE 1 — LEAVING NORMAL: THE EXPERIENCE OF BEING AIDS BEREAVED

Discussion of Themes

Confrontation with Death

In spite of the efforts the participants are making to deal with the huge numbers of losses that they have faced, this study reveals a lack of understanding of the magnitude and type of grief work required to resolve this amount of multiple loss. For many, myths about bereavement persist; for example: "time heals all wounds"; "Just put the past behind you;" "grief is just about crying and feeling sad;" and "grief work is over when you say goodbye at the funeral." The numbers of AIDS-related deaths that the participants reported reveal enormous reservoirs of grief and trauma in this group (an average of 127 deaths per person).

Undealt with losses linger. Without sufficient cognitive appreciation of grief tasks, people do not know how to identify grief in themselves or in another. This inability of mourners to recognize grief in themselves and others leads to inadequate peer supports in community and hampers their capacity to seek appropriate therapeutic supports.

The legacy of past losses remains, but the manifestations of those losses may be unrecognized as grief. In this study these manifestations of grief presented, in part, as intense emotional reactions: anger and rage, anxiety, shock, numbness, overwhelming sorrow, lack of focus and creativity, disorientation, and somatic (body-based) problems. Mislabelling reactions does not provide people with tools to get to the root cause of their distress; they are left managing reactions and behaviours rather than understanding the source of their volatile, or dulled, reactions.

Loss of the Assumptive World

The societal stigma attached to AIDS and homosexuality generates another layer of loss – the loss of security in knowing that one has a place in civil society and as a citizen is entitled to a societal response of compassion, not fear, blame, rejection, and hostility, in facing a catastrophic event. Thus, the loss of an assumptive world contributes to identity disruption, which correspondingly impacts how well individuals can re-establish a meaningful assumptive world: "The impact of multiple AIDS-related loss on the community exacerbates the impact on individuals and the impact on individuals exacerbates community-wide impact."[5] As a result, mourning the loss of the assumptive world, although difficult and complex, is an essential aspect of resolving AIDS-related bereavement.

The participants described creative coping strategies to mitigate and acknowledge these overwhelming losses: buffering themselves from the intensity of the pain through numbing, protective coping denial and efforts to manage chaos and recreate order. There appears to be value in large-scale memorial activities: the AIDS Quilt, the Candlelight Vigil, and the AIDS Memorial. These events are communal and visible and allow people to "dip in and dip out" of their grief responses as they memorialize the dead and reconnect with those who remain.

Survivor Syndrome

Survivor guilt is the term usually applied to this manifestation of traumatic loss.[6] However, the study participants described a wide range of behaviours, thoughts, feelings, beliefs, hopes, and fears – in addition to survivor guilt. Therefore, the term *survivor syndrome* is used to encompass their range of responses to the notion of surviving. Overall, the experience of survivorship is one of bewilderment that HIV and death seem to randomly pick some people and not others.

The participants also identified a paradox. Because so many have suffered and died while they remain alive, the participants felt that they are not entitled to a life with "big joy" or "big happiness." On the other hand, they feel compelled to "live and love big" in tribute to those who are no longer here, because they would have wanted a joyful life. AIDS bereavement interventions must incorporate the paradoxical notions of what a survivor is entitled to and responsible for.

Identity and Belonging

A significant challenge presented by AIDS is one of multilayered identity reconstruction. Mourners face the task of recreating a new identity on many levels: in response to the deaths of loved ones, as well as in relation to the loss of an assumptive world. Additionally, mourners are faced with the task of creating a new identity in relation to HIV/AIDS itself, whether or not one is HIV-positive or HIV-negative. This work of mourning an old identity and reconstructing a new one demands a flexibility and fluidity as community members also anticipate yet more losses to AIDS.

Making Meaning

The participants in this study frequently referred to the dimension of "meaning-making" or "finding meaning," or "making sense of the whole thing." This aspect of the AIDS bereavement experience arises as a consequence of the loss of the assumptive world and the shifts in identity caused by the magnitude of AIDS-related losses. Because the individual self is interpersonal at its very core, multiple losses are perceived as a threat to one's very identity.[7] Each loss is another loss to the self within a social network of meaning. The need to make meaning then becomes deeply and personally felt for the survivors of catastrophic AIDS losses. Making meaning for these participants involves a confrontation with the truth of what has happened and what is.

Rebuilding Community

As described in the literature, bereavement work is comprised of several distinct tasks: identifying what is lost, responding to the pain of the loss, reorganizing around the loss, and, finally, reinvesting once again.[8] The idea of reinvesting one's emotional energies in new relationships implies that the world as you knew it prior to the loss would be stable and recognizable as you complete your grief work. However, in catastrophic loss, in which the assumptive world is shattered, the final grief task of reinvestment now includes an additional, significant component—the need to recreate an assumptive world. Adequate bereavement supports for AIDS-related loss survivors must actively incorporate this task of reinvestment and rebuilding at both the individual and the community level.

The work of rebuilding devastated community life takes place in the context of uncertainty and ambiguity. AIDS is not over. Long-term survivors face a continual process of transforming, reinvesting, attaching, facing more loss, making meaning, taking on new challenges, losing again; and the cycle repeats itself. Bereavement models and grief supports currently available to long-term survivors rarely encompass this significant aspect of recreating an assumptive world and rebuilding community.

"What really matters to me is...."

The participants' descriptions of what really matters to them can be viewed as building blocks for programs that foster resiliency and develop communities. The following is a synopsis of the participants' concerns and passions about "what really matters:" a sense of belonging; authentic connections; meaningful participation in community life; being visible; being valued for one's struggles to survive; life experiences put to good use in community HIV-prevention efforts; and advocacy work; and access to structured peer supports. This list begins to identify what long-term AIDS survivors require to make the shift from survivor to thrivor status.[9]

Summary

The study participants painted a picture of an AIDS-loss terrain that encompasses both their turmoil and their positive adaptive strategies. The individuals described the significant impact of these losses on their emotional, physical, psychological, social, sexual, and spiritual functioning. The shattering of their assumptive world generates more loss responses at the same time that it decreases access to social supports that are essential to bereavement resolution.

The conclusions drawn from these findings point to: (a) a lack of awareness of the complexity and dimensions of AIDS-related bereavement; (b) the backlog of grief and loss in AIDS-affected communities; and (c) bereavement strategies and outcomes as part of community capacity building.

As health care practitioners, we need to ensure that the AIDS bereavement theories and practices currently being used by community-based service providers are sufficiently complex to meet the needs of the emerging populations of AIDS long-term survivors, both infected and affected.

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THE CONCEPT OF THE "OTHER" IN COUNSELLING: DIVERSITY AND CLINICAL IMPLICATIONS FOR A BETTER PRACTICE

Sylvia Tenenbaum[*]

Introduction: *Otherness* as a Problematic Term

The concept of the "other" in counseling analyses is multilayered as coexistent issues have created, and continue to perpetuate, an oppressive system by maintaining the dichotomist assumption of "us" and "them," thereby denying all of us equal and basic human rights. Any reputable mental health provider needs to engage in a profound self-reflective cultural practice to internally deconstruct what has been externally forced upon our day-to-day patients. Similar to diasporic studies done by the mainstream, where some individuals were forced to the margins of power and control, the mere term "other" implies gazing out upon a distance with a distinct division of place and time, that compounded with language barriers and cultural misunderstandings, could set the basis for a traumatic experience in therapy. Thus, the historical development of the patient identity by a mental health provider is embedded in otherness as a binary cosmovision. From a Eurocentric point of view, eugenics justified such control, and time became inverted space. Therefore, the primitive other was conceived as historically different on an ahistorical scale of human development, where his difference was merely a petrified sameness. Think of the patients that you assumed were heterosexual by denying other possibilities, or hidden disabilities, that were never disclosed in counseling because you did not provide a safe space to do so, or the refugee whose linguistic accent was equalized with a thinking accent. We have all a long way to go without any doubt, but a humble attitude could preclude a healthy first step towards a more just and joyful society.

Contextual framework

This article is designed to inform mental health providers in the field of counseling in the context of a multicultural, multi-ethnic, multi-faith, multi-gendered and multi-able Toronto. As such, Sherbourne Health Centre seeks to define and situate its psychotherapists within the broader historical, economic, and socio-political context of mental health care. Through a critical examination of some of the determinants of health, this article explores an understanding of the basic tenets in establishing a clinically non-oppressive practice with culturally diverse patients. Key concepts, such as class as a fluid construction, and the struggle against the essentialization or categorization of individuals, will be explored in relation to patients. Since ideas of gender and race are always shifting, and as we are multiple[1] as psychotherapists, then it is these very characteristics that are reflected in our patients.

Multiplicity as Advocacy

This article advocates for the inclusion of the concept of the "other" in everyday clinical practice. In order to accept and integrate such a concept, we need both intellectual familiarity and an openness to enter the murky waters of one's own psycho-social and sexual development. In keeping with our own complexity, we enact[2] many sexualities, many loves, and many longings. When practicing, we find these complexities mirrored in our clients. *Othering* creates distance and a false sense of control. Some psychotherapists intensified the otherness of their clients in order to avoid their own unresolved otherness, specifically oscillating between sameness and selfhood. If one can feel safe enough to explore and tackle the challenges that a diverse patient brings to the session, everybody benefits - at a personal, clinical, and societal level. Good multicultural counseling pertains to all three realms. Mental health providers should aspire to construct and deconstruct a strong therapeutic "third space,"[3] operating as a micro-cosmos and reflecting the changes conducted outside the sessions. I am a firm believer that the aim of therapy is to be able to live without therapy. The real challenges start right after each session, in the streets of Toronto - the not so good - for the disenfranchised, when daily bias and discrimination is confronted.

Clinical Implications for Urgent Changes

General questions frame particular ones. Why do we "other" patients? To feel more at ease with our privileges, perhaps to accept a more dormant existence. How do we "other" them? By denying history and constructing the so-called primitive. How can we counteract it? By intellectualizing oppression and the assumption of a political stand. As our patients share their vulnerabilities, we have a unique and precious opportunity to "create sanctuary towards the evolution of a healthier society."[4] For instance, many psychotherapists declare themselves to be "eclectic," which according to some, means being sloppy in their practice. Psychotherapy is an art, but also a social science, and as such, it needs to be based on current research and updated information. If we do not expand our psychological repertoire, we risk imposing our preferred technique on the client to our advantage, not theirs, and therefore, we are using our power to oppress them again. Rigidity on the part of the therapist is another form of oppression that clients sense. The increasing need for mental health experts within a diverse and anti-racist, anti-oppressive framework both urges and applauds a rejection of patriarchy as a model of "civilization," and opens a speculation of another look at the counseling process and its nuances.

History is a cultural construction embedded in mutable values and ever changing ethical dilemmas. Traditional studies of historical accounts have introduced the psychological process of othering individuals and cultures. Its aim was to define and control the "ambivalent," as well as to constantly impede certain groups from accessing privileges. It went from the imposition of stereotypes and labels, to its conjunction with the concept of "othering." The purpose served was/is to present an artificial framework as part of the "natural" order. When we do not accept the "weirdness" of a patient, their worldview, their way of being, even their own way of showing pain, we create a dangerous illusion turned prototype that becomes an ideal type, and then a theoretical model, in order to neutralize cognitive dissonances. Assuming a non-knowing stand is certainly more therapeutic than putting on a mask, for both patients and providers, as we can learn from each other and to enrich our encounters. We need to intellectualize oppressive practices[5] by particularizing the persons we engage in, and we could level the power by asking them to provide culturally competent interpretations.[6]

In today's multilayered society, a working relationship in psychotherapy addresses issues of otherness and fragmentation, as well as the constant battle of multiple oppressions in its psychological variables. Our patient's emotional priorities should dictate the counseling style. This is what Gramsci termed the elliptical formation of the subject, with its constant oscillation of in-and-out in our many selves, moving between the abstract and the concrete.[7] The subject in therapy expresses from a fixed – and usually conflictive – structure, to a more fluid, symbolic one. Similarly, the vision of a unified community is a fallacy, a myth. In that vein, being ethically consistent implies acting in a culturally appropriate manner, leaving the Eurocentric approach into a more ethno-specific one, and the sexually binary one to different manifestations of intimacy.

Neutrality in counseling is an oxymoron

Mental health counselors work with real people; individuals with unique, ethno-specific stories, values sometimes embedded in unconventional practices, peculiar choices, ambivalent sexual preferences, and difficult to understand underlying currents. Most of the therapeutic engagement is done by mere words. Yet, there is so much one can do by adding silence, a fruitful and respectful silence. However, a vast, deep, and/or well-articulated story event might be in the counseling session, silence is also a crucial part of that aspect.[8] Thus, a specific speculation of the issue of silencing in regards to our patients as perhaps the central mechanism of defining, maintaining, and alienating his/her stories in patriarchal history should be present when citing a case study or providing consultation about "them." As our words are tactically chosen, so is our silencing.

In fact, the study of others is never about them, but us, refracted through them, which in the end, creates our invented memory. This profound paradox of a real majority being both silenced and spoken for, voices our fears, and needs indeed further development.[9] I respectfully invite my colleagues to take into consideration that our patient's silence expresses a cornucopia of words, and even offers a form of embodiment of resistance.

To Gonzalo, who partakes my silence.

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[1] I have used the term multiple in a broad sense. While we access and overview both classical theorists and contemporary approaches, as mental health providers dealing with multiple diversities, we certainly operate by giving them a distinctive twist to the debate this psychotherapeutic models have engendered.

[2] The term "enact" is here used in Karen Maroda's sense, as a re-creation of an inevitable mutual event beginning with mutual projective identification, followed by mutual, unplanned behaviour, and culminating in a mutual sense of puzzlement and a certain sense of being emotionally out of control. The dangers of enactment are to be discussed in the session, and in the therapists' own personal therapy sessions. According to Maroda, as the emphasis on analytical treatment as a relationship continues to grow, all aspects of mutuality are being examined. Perhaps because of the threatening nature of the concept, analysts have not paid attention to the potential for recreating their pasts, sometimes in symmetry with their patients, at other times as an act of countertransference dominance that disrupts the treatment and may traumatize the patient. (Karen Maroda (1998). *Enactment: When the Patient's and Analyst's Past Converge.* Psychoanalytic Psychology 15:517-535.

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[4] Sandra Bloom cites: "In the haunted house of life, art is the only stair that doesn't creak", asserting that "every human advance is heralded by a flowering of artistic achievement" (248). This process shows its duality in a successful counselling engagement, if we are really committed as agents of sustained social changes.

[5] Foucault offers a disturbing analysis about the relationship between the traditional medical model from Medieval France on, criminology as an incipient science, and the current power of the medical establishment to diagnose, treat, "cure" and "free" individuals from their own demons (287). Foucault' elegant prose is a cautionary –nevertheless, necessary text for an informed therapist, as awareness of the power we hold is paramount to a fair and transparent practice.

6 Cultural competency for a person oscillating between the status quo and a diverse order (biculturality, cross-sexuality, etc.) refers to the concept of "symmetry building" termed by Van Eenwyk (1997), in which cultural patterns preserve their character through changes in their orientation. "When two or more attractors merge, patterns emerge that are more symmetrical than either of the original attractors, the result is considered to be a function of the original bifurcations" ("Self-organizing Chaos" 63). *Archetype and Strange Attractors. The Chaotic World of Symbols.* Inner City Books: Toronto.

7 Morton, A.D. "Historicizing Gramsci: situating ideas in and beyond their context" (pp.118-146). Vol.10#1, Feb 2003. Routledge..

8 Kristeva elaborates that when an immigrant is forced (or has chosen) to live between two words, silence might become the only common denominator (25).

9 According to Ricoeur, "the initial paradox is that of an "illusion" serving as an "expedient" on behalf of preserving life" (12).

FRAGMENTED SERVICES: FRACTURED CARE

Clare Freeman*

As an executive director of a violence against women shelter, I was recently at a community forum on homelessness with over 40 key mental health and community agencies. The co-relationship between homelessness, mental health, addiction and violence against women was raised over and over again by health care and community social services experts. However, what I noticed most at the forum was how little experts knew about the other discipline's services and how full collaboration between sectors was not present or encouraged. I started to wonder how many consumers we shared in common and how we might be failing them. I started to wonder how difficult it must be for the consumers we serve to feel fully valued when the services they use have fragmented their lives into separate disciplines. I also started to notice that people who struggle with multiple concerns are most likely to be denied one or more services because they do not fit into the one dimensional box that we sometimes require. As service providers, I believe we need to be developing cross-collaborative disciplines and services that transcend physical, funding and professional lines to eliminate fractured care services.

I have seen women who are fleeing a violent relationship come to our shelter with active addictions (drugs/alcohol), and/or severe mental health concerns and whose access to care is fractured. Violence against women shelters are not fully equipped to properly serve women with complex or untreated mental health and addictions in isolation of other services. Women will often remain silent about addiction and mental health concerns when they enter a women's shelter for fear of being asked to leave. Shelters can not adequately assess or address mental health and addiction concerns for the following reasons: building/service design; low staffing; the type of communal setting (supports women with or without children on-site and sometimes in shared bedrooms/bathrooms); lack of addictions and mental health training; and most importantly, insufficient funding.

From my experiences, mental health and addiction services may often deny or minimize the violence a woman may be experiencing in her life in order to treat her in their area of expertise. Mental health and addiction services inadequacies in addressing issues of violence in a woman's life may be due to the following factors: building/service design (they generally lack the security measures and procedures available at shelters); physical setting/communal space (they service women only without children on-site); treatment specific focus; and lack of community violence against women training and knowledge of interventions. The last factor may include such things as how to holistically assist woman with navigating a complicated legal system (women may often have both family and criminal court cases), as well as social support systems (housing, finances, employment, education and child welfare).

So what does this look like in reality? Two women fleeing violence may come to us with very different needs and concerns. One woman may be suicidal and experiencing night terrors while the other woman, her roommate at the shelter, may have a child who needs to get up early in the morning to be at a team practice. This situation can lead to poor service intervention for both. The woman who has a child may not appreciate being woken up by a women who is crying in the corner of the room and trying to cut herself.

What do we do as a service provider? We try to think of creative interventions, such as trying to get the woman with suicidal ideations and night terrors her own room. But, what do we do afterwards? Even if we can offer the woman her own room, this does not give her any treatment options. We do not have any mental health staff and even if we did, is this the best treatment site? We have had women attempt suicide on-site and after the emergency services intervene, the women are returned to our services within four hours without any treatment assigned. Our staff at the shelter have noticed the lack of psychiatric treatment and comprehensive care for our clients. Women have had multiple prescriptions and multiple diagnoses from multiple health care services with no follow-up.

Women also enter our service with active addictions. She may hide bottles and needles throughout the shelter. Another woman's young child may find the needles and begin to ask her mom "why does that woman want to put a needle in her arm?" Some women who reach our doors do not want to address their addiction issues. Some women are ready to address their addiction needs at the same time as they are leaving an abusive relationship; however, we cannot find any available spaces in addiction services. Without the addiction support, the woman may try to cope on her own but physical and psychological dependency needs often increase because of the stress and isolation of grieving an abusive relationship.

Community and mental health services have developed vast expertise in their own disciplines. What is needed now is for services to think about the holistic needs of consumers which goes beyond their individual services or discipline. They need to actively commit to finding ways to join or collaborate more closely in order to improve the quality of service and care. It is imperative that services not try to close the gaps in their services by excluding the already developed expertise in other disciplines. By working together, service providers can add knowledge, experience and support while challenging old assumptions and biases. This can only lead to better care and reduced fractured care, especially in the area of violence against women, mental health and addiction services.

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THE THERAPEUTIC INFLUENCE OF MEANING IN THE AFTERMATH OF TRAUMA

Jo-Ann Vis[*]

Introduction

Events are often categorized as traumatic if they are seen as sudden or unexpected, and believed to be life threatening or life altering. Often trauma exposure instils feelings of fear or a sense of helplessness, leaving individuals with a perception that they are unable to effectively respond to the situation. Trauma events are believed to be responsible for a variety of physiological and psychological discomforts which individuals typically report experiencing following the aftermath of a trauma experience.[1,2,3,4,5,6,7]

A review of literature depicts a variety of debates regarding the origins of trauma symptoms, uniqueness of experience and determinants of positive or negative outcomes.[8,9] On a continuum, one treatment perspective conceptualizes traumatic experiences as something from which people can and should recover, while on the other end, an alternative conceptualization offers that trauma experiences are transformative events, proposing that following a traumatic event, people themselves are changed forever. Subsequently, one approach to trauma intervention sought to support individuals with the goal to "get back to normal," while the other approach argued that the goal was not to fix or get over the experience, but to recognize and accept the process of transformation, integrating the person and who she/he was prior, during and following the traumatic event.

Through continued dialogue, this expanse on the continuum not only challenged and offered possibilities in response to what was traditionally accepted about trauma and trauma recovery, but offered the position that each individual's memory, response, understanding, or truth regarding the traumatic event was unique and real. Not only were researchers and practitioners then challenged to consider the possibility of unique responses to similar traumatic events, they also had to consider interventions that supported this uniqueness in ways that offered multiple views of a traumatic incident experience.[10,11,12,13] This paradigm shift included a new appreciation for the importance of meaning as part of an individualized response to trauma management.[14,15,16,17,18,19]

As a result of research and theoretical advances, three significant ideas emerged. First, is the argument that trauma is experienced as a whole being, which includes the individual's biological, psychological, social and spiritual self. Second, trauma experiences differ in terms of range, scope and intensity. Third, when exposed to trauma, individuals engage in some level of meaning formation following the event which can lead to growth, stagnation, or decline.

Implications for Intervention

What has been increasingly presented in the trauma research and literature is the connection between emotions and post-trauma development of memory. We no longer assert that memory develops in isolation. Similar to a strand of fabric woven within a sheet of cloth, memory connects and interweaves with other threads such as perception, meaning, emotion, and mood.[20,21] As a result, memory is not a simple video tape playback system of the concrete movements and actions related to a particular event; rather, each movement and action is interpreted, and this interpretation feeds into the emotions associated with the event. It is now argued that meaning, or the construction of meaning making of the traumatic event, has the potential to shape the perception of the event, and subsequently influence memory, emotions, and behaviour.[22,23,24,25]

When space is created for meaning exploration with trauma survivors, it aids in the development of a narrative that can become useful for individuals in their attempt to understand the impact of the experience. Exploring meaning through the process of developing a narrative provides a previously unexplored, but newly emerging, inventive approach to post-trauma stress disorder. "A few decades ago, based on the interest in humanistic psychology, the key word was "feeling." The more recent cognitive models have given primacy to ways of "seeing." In the future, I suspect that the growing interest in the metaphor of "voice" will point to a different way of "listening."[26]

Neimeyer and Stewart add to the concept of "voice" which includes the story, narrative, or belief about the role which an individual places him or herself in during and following the traumatic event. This theory adds to the complexity involved with trauma: it includes not only the trauma event itself, but the incidents before and following the event, incorporating the idea of people having many different selves. These authors conclude that the traumatic self becomes a barrier to other possible selves, and roles such as "victim," "injured," and/or "incapable" influence the recovery process. They believe that meanings or stories that individuals develop about themselves has an impact upon their ability to move beyond the trauma experience and see themselves as something other than a trauma survivor.

van der Kolk and Fisler report findings that support the idea that trauma memories are very susceptible to narrative influences. In a study of 46 subjects who were diagnosed with post-traumatic stress disorder, they found that the narrative of the trauma event evolved over time. Although the sensory recall, stored as sensory fragments, may have existed since the trauma event, the narrative developed later. The authors observed their subjects constructing a narrative that explained what happened to them as they became more aware of more elements of the trauma experience, either through conversations with others, sensory experiences, or other influencing factors. Their findings support the notion that memory is processed through verbal recollections, stories, and the meanings associated with them.[27]

Anderson[28] and Gergen[29] argue that the language that we use to conceptualize our understanding of people's behaviour develops problems. Within this context they believe that language, dialogical interactions, and even therapy are ways in which language can be used to explore alternative truths to the traditional empirical view of problems. They propose an alternative therapeutic approach in which cause and effect realities are replaced with the challenge that the cause and effect reality is but one truth, with the emphasis being placed on the constructed meanings by which we make our way through life.

Conclusion

When people think and/or talk about trauma, the initial constructed narrative about the event focuses on loss, suffering and despair. Although these narratives are expected initial responses for the majority of trauma survivors, they represent one response. Meaning exploration invites individuals to incorporate meaning beyond the immediacy of the event, possibly including a renewed appreciation for relationships, a new view on life, or a chance to make a difference in the lives of others.

Of course, it is important to recognize the loss and impact associated with trauma. What may be experienced or learned following the trauma event never will offset the pain and difficulty associated with post trauma recovery. But the fact that the story continues beyond the trauma event provides hope and an alterative view to suffering. Therapy which supports this expansion of meaning can offer individuals a process through which they can be exposed to different ways of viewing their *whole* trauma experience.

Tedeschi and Calhoun, in their work on post-traumatic growth, argue that for too long research has focused on negative after-effects of trauma and has minimized individual's ability to move past the trauma event with positive after-effects.[30] Research in the area of post-traumatic growth suggests that even though individuals continue to experience distress following trauma events, they also experience growth. It is argued that exploration of alternative meanings is a vital component in providing individuals with the opportunity to experience post trauma growth:

> A life narrative that includes the aftermath of trauma as having value, not merely despite the trauma, but because of it, has a more emotionally powerful positive quality and may motivate survivors to do something positive and possible with the memories of the trauma, rather than tackle the virtually impossible task of forgetting them.[31]

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UP IN SMOKE: PATIENTS' RIGHTS HAVE BEEN SACRIFICED ON THE ALTAR OF POLITICAL CORRECTNESS

T. Perry Ambrogio[*]

Kevin was a pleasant young man recently diagnosed with a mental illness. Bob was a crusty old fellow who had been in and out of psychiatric hospitals for years. But they had two things in common: they had both retained me to represent them before the Consent and Capacity Board, and they both were desperate for a cigarette.

I've represented hundreds of psychiatric patients over almost twenty years. Often, there is limited time to prepare for the hearing, so I'm determined to keep the interview focussed on the issues that will be before the Board; meanwhile my clients are anxious to tell me their complaints. Sometimes, the complaints are delusional in nature ("the doctor is trying to *poison* me"), but in recent years, I have found the complaints to be increasingly legitimate – especially when the complaints relate to smoking privileges.

In Bob's case, his situation was almost comical. He had limited off-ward privileges, and there was no smoking allowed inside the hospital. Bob refused to allow the staff to tell him when he could or could not go out for his nicotine fix, so he would smoke in the bathroom. The staff would bust him, and his limited privileges would be taken away as punishment. Now that he was confined to the ward, he had no choice but to try to sneak a cigarette and lighter into the bathroom, meaning that he would be busted again. When I interviewed him and asked him why he was challenging his involuntary status, Bob was very clear: he had to get out of hospital so he could smoke.

On the other hand, there was nothing funny about Kevin's situation. He had been recently diagnosed with a mental illness and was having difficulty coming to grips with the diagnosis. Somewhat understandably, the hospital considered him an "AWOL risk." This meant that he had no off-ward privileges. But Kevin was a smoker, and being without his cigarettes made Kevin (who was otherwise considered a pleasant and co-operative young man) angry, irritable and even hostile. He too was caught trying to smoke in the bathroom. When he refused to co-operate with staff, he was put into seclusion. Things escalated, and when he dismantled the air vent cover in the seclusion room, the staff called security. Although Kevin was not threatening himself or anyone else, when he refused to give up the pieces of metal from the vent cover, security called the local police. When Kevin refused to co-operate with the police, they decided to enter the seclusion room. While the horrified nursing staff looked on, the police "tasered" Kevin in order to bring him into submission, leaving marks which were still visible when I interviewed Kevin several weeks later. During our interview, it became apparent to me that more than anything else, he just wanted a cigarette. Ultimately I was able to negotiate a resolution for Kevin: the doctor agreed to give him smoking privileges, and he agreed to withdraw his application.

Like most non-smokers, I consider smoking to be a stupid and filthy habit. The fact that virtually all my psychiatric clients over the years have been smokers was difficult for me to understand. But several years ago, I was interviewing a client who was challenging the doctor's finding of incapacity regarding his finances. While preparing him for the expected cross-examination, I asked him "why would you spend 25% of your monthly income on cigarettes? Why don't you quit?" The man's answer has stayed with me all these years. "You don't understand" he said, "it's all I've got."

There is apparently a policy[1] within the Ministry of Health and Long-Term Care to encourage patients at psychiatric hospitals to quit smoking by not allowing smoking in the hospitals. However, anyone with even a rudimentary understanding of mental illness would know that this policy is unrealistic and destined to fail. Moreover, the policy is simply cruel; otherwise pleasant and co-operative patients become irritable and even dangerous when they are not allowed to smoke.

Of course there are other reasons why the non-smoking policy is a mistake. Imagine how much money is wasted on Board hearings that would not be necessary if some reasonable accommodation could be made for smokers in psychiatric hospitals. Imagine how many admissions are extended unnecessarily because of the breakdown in the therapeutic relationship between patient and treatment team which results from smoking-related conflicts. And imagine how much of the nursing staff's time is wasted in trying to police the non-smoking rules.

I recently mentioned this problem to a nurse at Regional Mental Health Care London. I asked him: "Wouldn't it be better for everyone if there was some way to allow smokers to smoke in the hospital?" He answered: "If you can arrange that, someone should give you a medal."

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[1] Section 9(8) of the *Smoke Free Ontario Act*, S.O. 1994, c. 10 permits mental health facilities to have a smoking room but the requirements are prohibitive and expensive.

THE DEMOCRATIC RIGHTS OF PERSONS WITH DISABILITIES: MAKING THE VOTING PROCESS ACCESSIBLE

Keesha Abraham *

About Elections Ontario

Elections Ontario is a non-partisan agency of the Legislative Assembly of Ontario which works under the direction of the Chief Electoral Officer. Elections Ontario is responsible for the organization and conduct of general elections, by-elections and referenda in accordance with the provisions of the *Election Act*,[1] *Representation Act, 2005*[2] and the *Taxpayer Protection Act, 1999*.[3] We also have responsibility for the administration of the *Election Finances Act*,[4] which regulates the registration of all political entities, political contributions, campaign spending limits, and political advertising.

Our vision is to set the standard for electoral process excellence. In fulfilling this vision, we recognize that the interests of the wide range of stakeholders involved in the electoral process in Ontario need to be considered. Their concerns are paramount to us. Electors want, and are entitled to, a convenient, simple and transparent electoral process.

Through Elections Ontario's Outreach Program, we exchange information with organizations that represent people with diverse needs. Our program strives to ensure that all electors are able to participate in the electoral process. We consult with a number of organizations in order to identify and address issues that may affect members of some of the following communities:

- Aboriginal peoples
- Persons who are blind or visually impaired
- Persons who are deaf, deafened or hard of hearing
- Multicultural/New Canadians

- Persons with a mental disability
- Persons who are homeless or have low income
- Inmates
- Persons with low literacy
- Persons with physical disabilities
- Seniors
- Students/Youth
- Tenants
- Residents of Shelters

We provide information and assistance to electors in these communities through effective, established products and services. For example, we provide community organizations with information packages to share with their members about how to register and how to vote – including how to obtain assistance from a deputy returning officer, vote at an advance poll, or vote by proxy. We are continually seeking ways to improve and enhance our Outreach Program.

Voting Requirements

To be able to vote in an election, a person must be 18 years of age, a Canadian citizen, reside in an electoral district in Ontario and must be on the voters list (or be able to have his or her name added to the list).

Elections Ontario strives to make the voting process accessible in a variety of ways to electors who may face barriers.

Identification

For the 2007 General Election, new legislation required all electors to show proof of identity before receiving a ballot. Electors who are not on the voters list are now required to provide proof of identity and residence in order to be added. The Chief Electoral Officer is required to determine a list of documents that will be accepted as proof.

To create this list, the Chief Electoral Officer asked organizations serving diverse communities for input before determining a final list of acceptable identification (this list is available at www.elections.on.ca). For example, in consultations with the organizations serving persons with mental disabilities, Elections Ontario was made aware that an overly restrictive list of documents would create a barrier for persons who have either lost or had their identification stolen.

Residence

According to the *Election Act*, a person's residence is the permanent lodging place to which, whenever absent, he or she intends to return. In the case of electors who are homeless, the place to which the person most frequently returned to sleep or eat during the five weeks preceding Election Day is his or her residence. After input from stakeholder groups, Elections Ontario developed a Certification of Identity and Residence form to permit administrators of shelters to provide a document which their clients, who did not possess identification documentation, could use to prove their identity and/or residence for voting purposes.

Assistance at the Poll

The *Election Act* also allows electors to have assistance from a friend or the deputy returning officer to mark their ballot. Electors unable to mark their ballot on their own may wish to have someone accompany them to the poll to help them complete the voting process. For polls in long-term care or institutional facilities, facility staff could assist by becoming deputy returning officers. The deputy returning officer is not limited in how many electors he or she may assist. When polls are located in institutions, it is often beneficial to have facility staff as deputy returning officers because they are more familiar with the patients or clients and have a better understanding of the accommodations they require. A staff member in this position would be required to work as a deputy returning officer all day.

Long-Term Care Facilities

In the case of clients in long-term care facilities, the *Election Act* allows for polling places to be located in hospitals and other institutions. If residents are immobile, poll officials can take the ballot box around to the bedsides of resident-electors. For the 2007 General Election and Referendum, there were 1,244 polls located in long-term care facilities.

Advance Polls

Some electors may find the voting process easier at an advance poll where it is less crowded and they can go through the voting process at their own pace. Caseworkers or administrators of group homes are encouraged to assist their clients by contacting their local returning office to find out what options are available to their clients. Returning officers are happy to work with caseworkers or administrators to determine a quiet time for clients to vote at an advance poll or have more poll officials available to help.

Proxy Voting

If for any reason, an elector prefers not to vote at an advance poll or on polling day, he or she may apply to vote by proxy by appointing another elector in the electoral district to vote for him or her at the election. Both the elector and his or her proxy will be required to provide identification to vote by proxy. Mental health workers are encouraged to contact their local returning office to obtain more information about the various options available for their clients.

Ballots

For the 2007 general election, the size of candidate names on the ballot was increased, making it easier to read. Party names were also added to the ballot, making it simpler for electors to cast their vote.

In addition to these specific initiatives, Elections Ontario trains election officials and call centre staff as to how to serve electors with disabilities. In addition, we also use plain language in our products, make our materials available in accessible formats and have pictograph posters in polling places.

Working with the Community

Prior to the 2007 General Election and Referendum, Elections Ontario met with key stakeholder groups in the mental health community to obtain feedback on how to better serve their community. Overall, these groups appreciated the opportunity to give input and provided helpful insights. They looked forward to future dialogues regarding accessibility.

Elections Ontario will continue to accommodate the needs of electors through effective products and services, including the following:

- Establishing and maintaining community relationships;
- Disseminating information to electors through established stakeholder groups;
- Providing information kits to administrators of facilities serving people with mental health disabilities;
- Providing access to registration and voting opportunities; and
- Ensuring access and accommodations at the poll.

Elections Ontario believes in building strong partnerships and working cooperatively with stakeholders to further our vision of electoral process excellence. We are committed to maintaining these relationships between events so that we can continue to find ways to make voting accessible for all Ontarians.

[*] Keesha Abraham is a Communications Officer with Elections Ontario.

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1 R.S.O. 1990, c. E.6.
2 S.O. 2005, c. 35, Sched. 1.
3 S.O. 1999, c. 7, Sched. A.
4 R.S.O. 1990, c. E.7.

MENTAL HEALTH AND FEDERAL CORRECTIONS

Howard Sapers[*]

Institutional corrections, by definition, takes place behind locked doors and involves some of the most marginalized members of society. For this reason, institutional corrections require oversight to help ensure accountability. The Office of the Correctional Investigator (the Office) was established in 1973 pursuant to the *Inquiries Act*.[1] With the proclamation in November 1992 of Part III of the *Corrections and Conditional Release Act*,[2] the Office was finally entrenched into legislation. The mandate of the Office, as defined by this legislation, is to function as an Ombudsman for federal offenders. The Office is independent of the Correctional Service of Canada (CSC) and may initiate an investigation on receipt of a complaint by or on behalf of an offender, at the request of the Minister or on his own initiative. As well, the Office has a responsibility to review and make recommendations on the CSC's policies and procedures associated with individual complaints. In this way, systemic areas of concern can be identified and appropriately addressed. The Office is required by legislation to report annually through the Minister of Public Safety to both Houses of Parliament.

The Office currently has twenty-four staff, including sixteen employees who deal with the day-to-day complaints of inmates. The Office receives between seven and eight thousand offender inquiries and complaints annually. Last year, approximately three thousand were addressed through an "immediate response" (the provision of information, assistance or referral) and nearly four thousand resulted in an inquiry or investigation. The investigative staff last year spent in excess of four hundred days in federal penitentiaries conducting interviews with more than twenty-five hundred offenders and met with inmate organizations at every institution in the country.[3]

Of the total 7,662 offenders' inquiries and complaints received by the Office this past year, the ten most frequent issues were related to:

1. health care (12%);
2. restrictions on, loss of, or damage to cell effects (9%);
3. transfers (8%);
4. administrative segregation (6%);
5. staff performance (6%);
6. case preparation (5%);
7. conditions of confinement (5%);
8. visits and private family visits (4%);
9. information – access and correction (4%); and,
10. grievance procedure (3%).

Offender complaints related to mental health services and delivery are part of health-related complaints and are relatively infrequent. However, mental health issues are often a key factor in many other complaints received by the Office. For example, offenders may complain about being placed in administrative segregation or transferred into a higher security penitentiary. After investigating, the Office often discovers that the placement in administrative segregation or the transfer to a higher security institution were the result of a disruptive behaviour due to a mental health condition. The correctional environment is not conducive to effective mental health interventions. In addition, this environment often compounds existing individual symptoms and in the absence of well trained staff, results in an escalation of inappropriate behaviours.

Mental Health Services

There are several international instruments which promote the protection of human rights of offenders. However, only the *Standard Minimum Rules for the Treatment of Prisoners*[4] makes specific reference to the treatment of offenders with mental disorders/illnesses and advocates for the provision of proper medical and/or psychiatric services.

Domestically, human rights protections are enshrined in Canada's *Constitution Act*.[5] Specifically, the *Charter of Rights and Freedoms*[6] protects basic rights and freedoms considered essential to a free and democratic society. Those of particular relevance to offenders with mental disorders include the right to life, liberty and security of the person, the principles of fundamental justice, the right to a fair trial, the right to be secure against unreasonable search and seizure, and the right not to be subjected to cruel and unusual treatment.

Federal offenders are excluded from the *Canada Health Act* [7] and are not covered by Health Canada or provincial health systems.[8] The CSC therefore provides health care services directly to federal offenders, including those residing in Community Correctional Centres. The CSC is legislatively mandated to provide health care to offenders through the *Corrections and Conditional Release Act* (CCRA).

Sections 86 and 87 of the CCRA state:

86. (1) The Service shall provide every inmate with
    - (a) essential health care (which includes mental health care), and
    - (b) reasonable access to non-essential mental health care that will contribute to the inmate's rehabilitation and successful reintegration into the community.

    (2) The provision of health care under subsection (1) shall conform to professionally accepted standards.

87. The Service shall take into consideration an offender's state of health and health care needs
    - (a) In all decisions affecting the offender, including decisions relating to placement, transfer, administrative segregation and disciplinary matters; and
    - (b) In the preparation of the offender for release and the supervision of the offender.

This responsibility requires the CSC to provide direct health services to federal offenders and therefore be fully equipped to provide these services. As a result, there are five regional mental health treatment centres (one per region) and four regional hospitals which provide post-surgical and palliative care within the 54 CSC institutions. In addition, Exchange of Service Agreements are in place for the provision of some services through provincial health care systems.

The 2003-2004 Annual Report of the Office included a special section highlighting the Office's concerns about the delivery of appropriate mental health services to federal offenders. By and large, it reflected the Office's support for the mental health strategy developed by the CSC. The CSC's strategy acknowledges that the proportion of federal offenders with significant, identified mental health needs has more than doubled over the past decade.

The CSC's strategy was released at approximately the same time as the study on health care needs of federal inmates was published in the April 2004 issue of *Canadian Journal of Public Health*.[9] This study indicated that inmates have consistently poorer physical and mental health as compared to the general population, regardless of the indicator chosen. Indicators include: socio-economic measures such as level of education and unemployment; health behaviour, such as smoking and substance abuse; chronic conditions, including diabetes and heart conditions; infectious diseases, such as HIV and tuberculosis; mental heath disorders, including schizophrenia and mood disorders; and mortality, such as homicide and suicide.

The Office's 2004-2005 Annual Report stated that mental health services offered by the CSC have not kept up with the dramatic increase in numbers of inmates with mental health issues. The level of mental health programming available continues to be seriously deficient. This has been further highlighted by a review on mental health, mental illness and addiction conducted by the Standing Senate Committee on Social Affairs, Science and Technology, chaired by the Honourable Michael Kirby. In the Committee's interim report,[10] the Committee concurred with the CSC's conclusions that:

- the CSC must have a greater capacity to respond to the needs of offenders to gain access to mental health services and addiction treatment;
- the CSC's five treatment centres are not resourced at levels comparable to provincial forensic facilities;
- psychologists are primarily engaged in risk assessment for conditional release decision-making as opposed to treatment and rehabilitation; and
- there is no specific training for front-line correctional staff on mental illness and addiction.

The CSC's strategy promotes the adoption of a continuum of care from initial intake through to the safe release of offenders into the community. The strategy indicates that significant investments are required in the following four major areas:

- comprehensive clinical intake assessment;
- specific requirements for enhancing the CSC's Treatment Centres;
- intermediate mental health care units within existing institutions to provide on-going treatment and assessment during the period of incarceration; and
- community mental health to support offenders on conditional release.

The Office was pleased that the Executive Committee of the Correctional Service of Canada fully endorsed the above four-point strategy in 2005. More recently, the current Commissioner has identified mental health issues as one of his five top corporate priorities.

In 2006, the CSC tabled its Report on Plans and Priorities before Parliament, which made it clear that the gaps in the delivery of mental health care and services to federal offenders need to be addressed on a priority basis. The CSC has since secured five-year funding to strengthen mental health services provided in the community, and has secured two years of funding to improve the early identification of offenders' mental health issues and to ensure that their needs are better addressed throughout their sentence.

The Office welcomed the news of these new investments in community mental health to alleviate the increasing demands for adequate mental health services. However, the overall situation of offenders suffering from mental health issues has not significantly changed since the Office first reported the troubling situation back in 2004. The CSC's Mental Health Strategy must be fully implemented with new and permanent funding secured. Prompt and permanent funding to enhance CSC's capacity to meet its legal obligations regarding the delivery of mental health care and services to federal offenders is urgently required.

Conclusion

Meeting the needs of offenders who suffer from serious mental health issues is a key part of effective corrections. Failing to meet these needs has significant adverse effects on both offenders and society in general. Offenders with mental illness are more likely to be: segregated; involuntarily transferred to higher security institutions; subject to unnecessary use of force interventions; victimized by other offenders; and released later in their sentence. Many of these offenders do not have the skills or capacity to achieve success in correctional programming or to formally raise concerns regarding programming and treatment to correctional authorities or external agencies, such as this Office.

Public safety will be enhanced if we ensure that offenders with mental illnesses are released back in the community after having received adequate care. The welfare of our federal inmates is a public issue. The vast majority of inmates are one day released into society. It is beneficial for everyone if these offenders return to society having received adequate mental health services and rehabilitative programs. All of us have a vested interested in treating offenders with humanity and helping them to lead productive and law abiding lives – during incarceration and on release.

The Correctional Investigator's Office remains seriously concerned that the needs of offenders with mental health issues are not being met and that the efforts by the CSC to secure permanent and adequate funding have not yield the desired results. The capacity of this Office to actively respond to the growing numbers of offenders with mental health issues is also limited. We can envision the benefits of the introduction of a patient advocate model in the five CSC Regional Treatment Centres as a means to ensure better protection of the rights of federal offenders suffering from serious mental illness. The addition of a patient advocate model would complement the work of this Office and enhance accountability, as well as ensuring better legal and policy compliance. The experience and successes of the Ontario Psychiatric Patient Advocate Office could serve as a useful model should such an initiative be considered for federal corrections.

*Howard Sapers is the Correctional Investigator of Canada.

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[1] See Part II, R.S., 1985, c. I-11.

[2] S.C. 1992, c. 20.

[3] *2006-07 Annual Report of the Office of the Correctional Investigator* (Annex A).

[4] U.N. Doc. A/CONF/611, annex I, E.S.C. res 663C, 24 U.N.ESCOR Supp. (No. 1) at 11, U.N. Doc. E/3048 (1957), amended E.S.C. res 2076, 62 U.N. ESCOR Supp. (No. 1) at 35, U.N. Doc. E/5988 (1977).

[5] *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

[6] Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

[7] The *Canada Health Act* defines publicly funded health care insurance. The *Act* sets out the primary objective of Canadian health care policy as: "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers." However, the *Act* specifically excludes "persons serving a prison term in a federal penitentiary."

[8] Health Canada has neither the infrastructure nor the mandate to provide any direct health services, including mental health services, to federally incarcerated inmates.

[9] See www.cpha.ca.

[10] The report is entitled *Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada* (November 2004). It can be found at www.parl.gc.ca.

AN OVERVIEW OF THE SECURE TREATMENT UNIT – A UNIQUE FACILITY FOR SPECIAL NEEDS OFFENDERS IN EASTERN ONTARIO

John M.W. Bradford* and Robyn Griff**

There have been increases in the number of mentally ill offenders being detained in correctional facilities worldwide.[1] Many studies and articles have been written to describe this phenomenon that is now termed *criminalization of the mentally ill.*[2] About 9 million people are imprisoned worldwide and a recent meta-analysis of 62 surveys from 12 countries, including 22,790 prisoners, clearly showed that several million prisoners worldwide have serious mental disorders.[3] The rate of serious mental disorders for prisoners is several times what is seen in a general population. In brief, it is argued that this is the result of an inadequate mental health system, wherein persons with serious mental illnesses end up in the correctional, rather than the mental health, stream.[4] Besides the human cost to the individuals caught up in the system, the cost to society is also significant resulting in: increased recidivism of mentally disordered offenders; poor quality of life; homelessness; and a general increase in the stigma associated with having a major mental disorder.

Another phenomenon emerging in the 1980s was *deinstitutionalization*, which is defined as the translocation of patients from hospitals to alternative settings. This has also been a worldwide trend. In theory, the theory underlying deinstitutionalization was that patients discharged from psychiatric facilities would be managed effectively and treated effectively in the community. Some of the difficulties associated with deinstitutionalization were the theoretical assumption that all psychiatric patients could be managed in generic community facilities and assumption that "one size fits all." Inadequate social housing has led to homelessness; homelessness has led to a loss of contact with the mental health system; criminalization has followed homelessness.[5] In Ontario, the number of psychiatric beds had remained relatively static since 1980 (in 1980, there were 4,948 psychiatric beds in Ontario; in 2004, this number was reduced to 4,928).[6] Arguably, however, much of the reduction of psychiatric beds occurred prior to 1980. Research demonstrates that the prevalence of mental illness in the growing homeless populations of Canada's cities is at a high-level; additionally, a significant number of these individuals end up in correctional facilities.[7] In Ontario, there have been increased numbers of forensic psychiatric beds added to the system to try and deal with these difficulties. Moreover, various programs have been given significant funding in an effort to keep people with mental illness outside the criminal justice system, including: court diversion programs; mental health courts; and supportive housing.

Another solution is the move to better integrate the various ministries involved with mentally abnormal offenders – namely, the Ministry of the Attorney General, the Ministry of Community Safety and Correctional Services (MCSCS) and the Ministry of Health and Long-Term Care. Increasingly, linkages between these ministries have developed to address the problem from an inter-ministerial standpoint. One of the results of this level of cooperation is the Secure Treatment Unit (STU) of the St. Lawrence Valley Correctional and Treatment Center located in Brockville, Ontario. This facility is jointly funded by the Ministry of Health and Long-Term Care and the MCSCS, with the latter ministry being the lead Ministry.

The STU is a 100 bed Schedule 1 facility located within a medium-maximum correctional complex for provincially sentenced male offenders for all of Ontario. MCSCS contracted with the Royal Ottawa Health Care Group's (ROHCG) Integrated Forensic Services in 2003 to provide provincially sentenced male offenders with psychosocial rehabilitation and criminogenic needs specialized mental health services. This collaborative model of combining the expertise of provincial corrections and mental health care is the first such partnership in Canada. The collective mandate is to reduce symptom distress, criminogenic attitudes and behaviour while increasing psychosocial skills, coping strategies, and subjective well-being with a long term goal of contributing to reduced recidivism.

The uniqueness of this facility is, first and foremost, its therapeutic milieu. This is characterized by four specialized units of 25 individual resident rooms, carpeted hallways, clear sightlines unencumbered by bars, maximum natural light and the provision of care by a team of interdisciplinary health care providers. The security and transportation of residents is the role of corrections.

A service agreement with specific performance outcomes clarifies the role each partner has in serving this special needs population, which is closely monitored by a MCSCS compliance officer.

The STU provides an academic health science centre level of care with an interdisciplinary model of care and services to this complex patient population. Their average age is between 25 and 34 years, the majority of whom are transferred in from outside the Southeast/Champlain region. Residents present with a broad spectrum of diagnoses, which range from personality disorders to impulse control to sexual disorders to psychotic disorders. More than 90% of these residents have a co-morbidity with substance abuse and psychosocial stressors.[8]

On admission to the STU, an extensive assessment is conducted, which translates into an individual treatment plan. Diagnoses and medications are reviewed and the resident (not offender) is then assigned to one of the four specialized units – Trauma, Sex Offending, Personality Disorders or Admissions. The treatment plan is initiated immediately, and at the same time, a discharge plan is formulated.

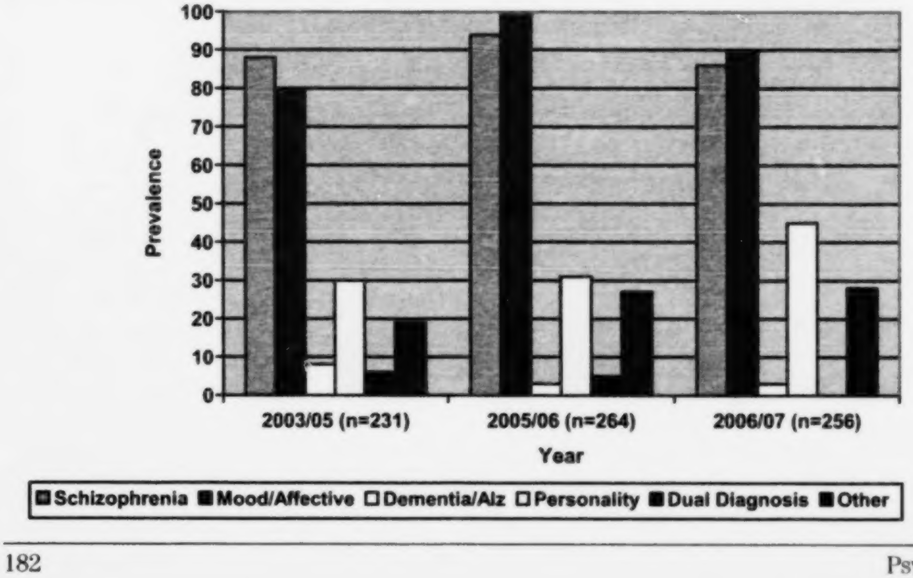
An interdisciplinary team facilitates the following specialized treatment groups:

- Living without violence;
- Anger and emotional self-regulation;
- Pro-social attitudes and lifestyle;
- Self-regulation for sexual offending; and
- Substance abuse psychotherapy.

86% of discharged residents participated in these groups. Groups are open-ended to accommodate resident participation, regardless of length of stay. The majority of residents have less than one year remaining in their provincial sentence when transferred to the STU.

A wide variety of psycho-educational groups are provided. Residents are referred based on assessed individual need, regardless of length of stay. Other programs facilitated by allied health professions are offered as part of a holistic therapeutic approach to care, including education, literacy, recreation, spiritual and vocational programming.

The effectiveness of this model is being reviewed. Preliminary data collected has produced favorable results. MCSCS identifies the Correctional Program Assessment Inventory (CPAI) as the tool to assess improvements of skills, attitudes and behaviours. An assessment was conducted in March 2007.



ROHCG measures clinical improvements by administering the Brief Psychiatric Rating Scale (BPRS) and Quality of Life Scale (QOL), as well as using Global Assessment of Functioning Scale (GAF) scores to evaluate overall effectiveness of treatment interventions. BPRS measures acuity of symptomology and a review of admission and discharge scores reflect a *decrease in symptoms post treatment intervention*. The QOL scale measures overall clinical improvements in skills, attitudes and behaviours as a result of treatment interventions. This tool has demonstrated *a significant level of improvement in quality of life post treatment interventions*. GAF testing *demonstrates improved health and well-being*. The BPRS is the most commonly used objective measure of individual psychopathlogy. The GAF score from the DSM-IV is a 100 point scale that measures psychological, social and occupational functioning on a continuum of mental health and illness. The higher the score, the lower the level of impairment.

Being a unique facility, the STU is being used as a testing ground for other types of evaluations and measures. Such tools as Decision Base software, the Resident Assessment Instrument (RAI), along with a newly developed Forensic Supplement to the RAI to assess violence, and a modified Quality of Life Scale, are all being piloted at the STU.

This collaborative model of custody and care for the seriously mentally ill offender in Ontario is proving to be a success. Part of the success is the post-sentence diversion of the mentally ill offender back into the mental health care system at the end of their sentence. It is hoped that in the future that a partnership to address the needs of the female mentally ill provincial offender population may become a reality. In addition, it is hoped a partnership with the Correctional Service of Canada to deal with mentally abnormal offenders in the federal system may also be developed.

Key to the success of this model is the shared expertise of the criminal justice and mental health systems. Professionals who see that flexibility and adaptability in the way this unique population is secured and treated has produced effective outcomes for all involved.

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1 S. Fazel and J. Danesh. (2002). Serious mental disorder in 23,000 prisoners: a systematic review of 62 surveys. *Lancet, 359*(9306), 545-550.

2 A.J. Grudzinskas, J.C. Clayfield, K. Roy-Bujnowski, W.H. Fisher and M.H. Richardson. (2005). Integrating the criminal justice system into mental health service delivery: the Worcester diversion experience. *Behav Sci Law, 23*(2), 277-293.

3 *Supra* note 1.

4 *Supra* note 2.

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6 Ontario Forensic Directors Group. (2007). *Range of Forensic Services in Ontario.*

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WIDENING THE NET

Elizabeth White[*]

The dichotomy of whether a person who has a mental illness and is in conflict with the law is a criminal or a patient has frustrated both our health and justice systems for decades. How one is categorized has determined both access to services and attitudes towards the individual. The matter is not trivial because it causes a ripple effect in terms of allocation of resources and, ultimately, the safety of the person and the public. The growing numbers of sentenced people with mental disorders has resulted in an increased focus on providing interventions to improve the quality of their lives and the safety of the public. Many are promising practices but much more must be done.

The exciting premise of deinstitutionalization, that people with mental illness belong in their community, faded with the realization that the community was not equipped to provide adequate, or, in some cases, any services to meet the range of presenting needs. Lack of training and resources to support successful interventions resulted in people falling through the cracks of the social safety net with tragic results. One particularly distressing outcome was the increased numbers of people with mental disorders coming into conflict with the law. Bearing the dual stigma of conflict with the law and mental illness impeded one's ability to obtain treatment and enter programs. The detrimental effects are recorded in the research.[1]

Both the provincial and federal departments responsible for corrections have allocated resources to studying the situation, as well as designing and implementing interventions for people with mental disorders within their jurisdiction. However, the numbers continue to be significant and long-term outcomes are not yet available.

The Ontario Ministry of Community Safety and Correctional Services (MCSCS) estimated in March 2007 that as many as 446 sentenced offenders on any given day suffer from past or present mental illness. Part of their response has been the creation of the St. Lawrence Valley Correctional and Treatment Centre in Brockville, a one hundred bed correctional facility which has an agreement with the Royal Ottawa Health Care Group to provide clinical services. Comprised of four units focused on different needs, the program offers comprehensive multi-disciplinary assessment and treatment. It maintains a high occupancy level and average length of stay has increased steadily over the almost five years of operation.[2]

The Correctional Service of Canada (CSC) is in the midst of a five-year initiative to expand its community programming with support nurses and training on mental health issues for parole offices, community correctional centres, and other community service providers to better link offenders with appropriate services during reintegration. With 12% of sentenced men and 25% of sentenced women diagnosed with mental health problems, CSC intends to address the needs of those within their mandate to provide essential health services and support a successful reintegration process.[3] Structured Living Environments were designed and implemented in institutions specifically for mentally disordered women. Regional Treatment Centres provide intensive care for those with acute disorders. A five-point strategy from assessment to transition to community is underway and the CSC is currently adding to its mental health professional staff.

Re-entry to community is a critical time and is particularly problematic for offenders with mental disorders. CSC staff may accompany a released prisoner for the first day to assist with the necessities of living out in the community.[4] Community-based transitional residences struggle to accommodate these individuals in their programs. The imperative of specialized training and enhanced programming (particularly an increased staff/resident ratio) has been a significant cause for concern in the context of both the resident's and the public's safety during conditional release. In prison, accountability for access to service and mandate is clear; however, once a person is on conditional release, multiple mandates come into play. Federal, provincial, and municipal services may all be relevant to any one individual and coordination and collaboration among them is key to developing the safest platform for community reintegration. Community agencies face limited resources for training and capacity to provide effective interventions, especially for high needs residents. Nonetheless, some very encouraging programs have been developed and these may well prove models for the future.

Gallagher Centre[5] provides short-term crisis support beds for three adult men with mental health issues as an alternative to hospitalization or incarceration. Maison Louise Arbour[6] provides residency, assessment and counselling for women with similar programming. Funding for both is through the Ministry of Health and Long Term Care's (MOHLTC) Service Enhancement Investment targeted to reduce the likelihood of people with mental illness (re)entering the justice system. Another Gallagher program is a Supported Independent Living Program, which provides residency for three high risk men with mental health issues or developmental disabilities, including sex offenders, and one-to-one intensive community support. Protocols with police to address the high profile nature of this clientele are in place and funding is multi-sourced including MCSCS, CSC, Ministry of Community and Social Services and the Children's Aid Society.

Elizabeth Fry in Kingston designed a position for a community-based mental health worker who assists federally sentenced women with a high rate of mental health disorder and/or low functional abilities in all aspects of their community integration from securing housing, to employment and recreational support, and daily living skills. Community agency staff are trained in the special needs of the women. The program provides a continuum of service from institution to community and involves collaboration with CSC staff and Kingston area mental health and social services.

A further challenge is that those charged with the care and management of sentenced mentally disordered persons have competing, and potentially conflicting, priorities - risk evaluation and management versus treatment. At stake is how interventions are developed and deployed to meet the needs of particular groups. The issue of competing interests in social control and effective social rehabilitative intervention plays out throughout the continuum of the criminal justice system.[7] Recently, risk management has overshadowed support services. To date, research on services (primarily psychological) delivered to offenders in the context of their treatment plans do not conclusively demonstrate successful rehabilitation outcomes.[8] Other research finds mental illness to be a correlate of criminality (rather than a cause as is sometimes posited). It follows then that the goal of intervention should be at least as much offender-focused as it is offence focused.[9]

Concern about these issues led St. Leonard's Society of Canada and the Canadian Criminal Justice Association to develop four cross-sectoral fora to share insights and propose exemplary practices for national distribution. In November 2007, we held structured discussions composed of keynote presentations, active participation by each invitee and development of recommendations for a model community mental health strategy in each of Kingston, Halifax, Calgary and Vancouver.[10]

Of note in each venue were both the high quality of existing programs and committed professionals and the limited familiarity that many had with each other's work – a result of too little time and too few resources to devote to collaboration.

All acknowledge that cross-sectoral efforts are needed. Mental health agencies have difficulty managing sentenced persons in their programs. Transitional housing services grapple with a lack of training on mental health issues. Police and hospital staff expend tremendous energy and resources in responding to presenting needs. Prisons and jails are the unwilling shelter of last resort. Yet, while all agree that a silo approach is not optimal, barriers of funding, common language, mandate and differing focus hamper collective work.

Fora participants had no difficulty in identifying elements necessary to ensure access to quality mental health services and supports for sentenced persons. From the simple to the systemic, some suggestions were:

- Information-sharing between systems while respecting patient privacy, perhaps by a document that individuals carry with them.
- Implement a plan for the person before addressing the risk to society factor. Ensure that the individual and his/her needs are the core concern.
- Policy needs to be set within the context of existing research, not driven by popular misconception.
- A dual focus on short-term stay and long-term community support is required given that mental illness is a life-time factor that can be in remission but that can relapse.
- Comprehensive assessments on admission to institutions.
- Hospitals need to be a part of community initiatives and continuum.
- A focus on the individual and their human rights.
- Without safe and supported housing little else matters.

In Kingston, Dr. Arboleda-Florez[11] challenged the current provision of mental health services. The use of acute care interventions which involve short-term hospitalizations not necessarily followed by longer term support and programming impedes the continuity of care which would optimize the ability of the patient to manage community living. He commended an information-based approach with a patient focus that respects their rights, a continuum of care beyond the hospital and the least restrictive interventions.

Nobody underestimates the challenges of providing appropriate effective interventions. Police are particularly affected as first responders to disturbances and crisis situations. Where police are able to enter into effective collaborations with social service providers, criminalization may be avoided.[12]

The issues of co-morbidity, incongruent mandates, continuum of care, and lack of training across disciplines defy simplistic response. Accessing psychiatric services while on conditional release is extremely difficult and there are long waiting lists, especially for people with dual diagnosis. Furthermore, the marginalization of the field as a specialty and resultant shortage of trained professionals, dedicated resources and lack of research must be overcome. The stigma of the patient/prisoner extends to the professionals who work with them, hampering development of better practices and policies.

Optimism is found in the creation and mandate of the Mental Health Commission of Canada. It may be able to address such stumbling blocks as the inconsistencies among the various legal mandates, the knowledge gaps, and public perception.

Avoiding criminalization, reducing recidivism and improving the quality of life of the patient/prisoner requires the safety net to be strengthened by: building networks, supporting a continuum of care; training service providers based on a platform of understanding and knowledge of existing resources; and intervening with youth and children at the earliest opportunity.

The wealth of promising practice and good will in all four cities is encouraging. Sharing and learning from each other hopefully will widen the safety net and reduce reliance on the blunt and damaging tool of incarceration.

*Elizabeth White is the Executive Director of the St. Leonard's Society of Canada.

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2 For the year ended March 31, 2007, average length of stay was 131 days.

3 As of November 2007, CSC reported 33 train the trainer program attendees, and 121 staff attendees at the two day mental health training program. The program continues.

4 For example: Releases from the Kingston Regional Treatment Centre, co-located with the Kingston Penitentiary, are supported by Beyond the Drive: The Accompaniment Support Program. Staff help with such things as paperwork for a health card, setting appointments with social services and parole, and, most crucially, making sure that there is housing for the night.

5 A sixteen bed residence operated by St. Leonard's Community Services London and Region (SLCS). A formative evaluation of the Crisis Support Program indicated more than 90% of residents had a serious mental disorder and more than 80% had a history of violence. However, many lack a formal diagnosis which hampers acceptance

to community mental health agency programming. An example of the difficulty that can crop up in cross-sectoral initiatives is that the MOHLTC has no means to provide health cards to these men as they are not eligible for the Disability Support Program owing to their status in the correctional system. (Correctional institutions provide health care as part of their mandate.) However, SLCS is neither an institution nor are the men out of the criminal justice system – so the cost of their medications, which are many, falls to the agency.

6 SLCS residential program for women.

7 "The growth of forensic psychiatry may be due to changes in the law and to a more liberal acceptance of psychiatric explanations of behavior, but a more immediate reason is the large number of mental health patients in forensic facilities, jails, prisons, and penitentiaries. Failures of the general mental health system may, therefore, be at the root of the growing importance of forensic psychiatry." Arboleda-Florez, J., (2006) Forensic Psychiatry: contemporary scope, challenges and controversies. *World Psychiatry*, 5(2), p.88-89.

8 Blackburn, D., (2004). "What Works" with mentally disordered offenders. *Psychology, Crime and Law, 10(3)*, p. 297-308.

9 *Ibid.*, p.301. Blackburn further notes that reduced recidivism alone is not an adequate criterion for treatment efficacy.

10 Support for the project was provided by Public Safety Canada and the Law Foundation of Ontario. For more details, contact either organization.

11 Dr. Arboleda-Florez is Professor Emeritus at Queen's University in Kingston, specialist in forensic psychiatry. He delivered the keynote speech and sponsored the Kingston Forum.

12 One example of an active protocol is L.E.A.D. (Lanark County Police Services and Lanark County Mental Health, Emergency Department, Ambulance Services, Diversion). The purpose is to better serve the community and, specifically, emotionally disturbed persons in crisis. It works to increase training of the L.E.A.D. Team Members and be a partnership with local mental health care professionals and advocacy/support groups.

MENTAL HEALTH COURTS

Justice Richard D. Schneider*

In a perfect world we should not need mental health courts, let alone literature about them. But we do. Realistically, in a less than perfect world we should perhaps aspire to see mental health courts as part of our future but not as the full 'answer to the problem' as they are currently seen. 'The Problem' is that over the past 15 to 20 years the criminal justice system has had to contend with ever-increasing numbers of mentally disordered individuals coming through the court house doors. This has occurred as the provision of mental health care services in most communities has witnessed a steady decline. Beginning with the deinstitutionalization movement occurring in the later half of the 20th century, adequate mental health care services became increasingly scarce. There has been a movement toward community-based treatment of major mental illness which in many instances appears to be insufficient. Despite what was promised, the money saved with the closure of hospitals has typically not been re-invested in community treatment, or, invested ineffectively. At the same time, while it is acknowledged that community-based mental health care is an important component of the mental health care system, it cannot address the needs of many of the more seriously afflicted individuals.

It goes without saying that decreasing mental health care services does not lessen the needs of those members of our society who rely on such services. For these individuals, closed doors and long wait lists have offered little. Regrettably, those unable to receive adequate services often find themselves attracting the attention of the criminal justice system, leaving that system to "sort out the mess". In some jurisdictions, mentally disordered accused entering the criminal justice system have increased at a rate in excess of 10% *per* year over the past dozen years.[1]

Understandably, the criminal justice system has not delivered. The criminal justice system was neither designed nor intended to address society's responsibility to the mentally disordered individual. Even a basic familiarity with the traditional criminal justice system will reveal that it is no substitute. Undoubtedly, it is worse. Accused persons with mental disorders languish in detention centers and correctional facilities. They often fail to receive much needed treatment, typically feel alienated and marginalized, and generally have a difficult time re-gaining stability in the community once entwined in the system.

Mental health courts are a response to this reality. Recognizing the criminalization process which has occurred, these courts have sought to reverse the misplaced responsibility for the provision of mental health care services. These courts have various objectives which include the targeting of accused with mental disorders and have as their mandate one or more of the following objectives:

1. 'diversion' of accused who have been charged with minor to moderately serious criminal offences and offering them an alternative;
2. expediting the pre-trial processes of assessing fitness to stand trial;
3. treatment of operative mental disorders; and
4. a slowing of the so-called 'revolving door'.

Through successful participation in a treatment program overseen by a mental health court team, some accused can avoid conviction and sentence, as they are 'diverted' back into the civil mental health care system. Some jurisdictions have included diversion as a component of their mental health court but have attempted to also intervene at multiple post-arrest junctures and to a much larger population of mentally disordered accused.

In beginning to appreciate mental health courts, it is necessary to understand the principles of therapeutic jurisprudence. It is a theory which holds that the law should be administered and applied in a way which incorporates therapeutic goals. It advocates using the justice system in a manner which addresses the underlying factors which may lead an individual to come into contact with the law. It is a vehicle to obtaining a better societal response to proscribed behaviours. Mental health courts often focus on treatment, housing, substance-addictions, job-training, and other matters in preference to such traditional options as jail, fines, and probation.

Mental health courts find promise in offering treatment instead of punishment. Their ability to effectively remove individuals from the criminal justice system through the provision of services demonstrates an important reality: for many accused, minor offences may more accurately represent an inability to control or manage their mental health symptoms as opposed to deliberate criminality.

Understanding the operation of a mental health court requires an appreciation of both the mental health court team and the eligibility of accused for program participation.

While the 'nuts and bolts' of mental health courts will vary, integral to the functioning of a mental health court is a multidisciplinary team approach. Judges and lawyers are supplemented by any number of psychiatrists, psychologists, case workers, and social workers who collaborate on how the particular needs of the accused can effectively be met. The various disciplines represented in these teams form a concentrated resource which facilitates the court's operation.

Each court maintains a formal or informal policy outlining the type of accused eligible for the court. Typically, participation in the 'diversion' component of a mental health court is reserved for individuals with mental disorders charged with minor to moderately serious offences. Nevertheless, certain courts also provide services which do not involve eligibility requirements. As an example, the Toronto mental health court, addresses the pre-trial issues of fitness to stand trial and treatment of underlying mental disorder for all accused, regardless of the seriousness of the offence. As well, the court may order assessments to determine the issue of criminal responsibility. On a voluntary basis it will also entertain resolutions and bail hearings. While the mental health court in Toronto was the first in Canada and the only one to operate on a full-time basis, mental health courts are in operation in Ottawa, Newmarket, London, and Brampton, and others are in the planning stages.

As previously noted, a primary goal of mental health courts is to re-connect and reintegrate individuals in need of treatment to the appropriate services. Thus, mental health courts form bridges to various services within the community. Assisting individuals to manage their mental disorders through the provision of mental health and social services reduces the likelihood of subsequent offences and in this way, mental health courts also seek to curb the disproportionately high rate of recidivism in this segment of the population. With a reduction in recidivism, the courts also make communities safer places to live. There are now studies which support the previously intuitive projection that mental health courts do indeed reduce recidivism rates.[2]

Mental health courts do not share the hard-hitting adversarial atmosphere associated with most criminal courts; actually, mental health courts hardly feel like courts at all. An informal atmosphere aimed at putting the participants at ease and fostering an environment conducive to discussion is a feature common to all mental health courts.

It can be stated that mental health courts have emerged out of frustration and an abhorrence of the realities faced by mentally disordered accused. Lengthy delays for fitness assessments, a cast of courtroom players untrained and/or unfamiliar with the realities of mental illness, and a prison system more prone to exacerbate than to manage, only begins to enumerate the list. These courts are often held to be direct commentaries on the failure of the traditional justice system to meet the needs of mentally disordered accused. But, even more, they are commentaries on the failure of the civil mental health care systems to adequately address the needs of this population. While mental health courts provide a very good short-term fix to this social problem, they should probably not be seen as the ultimate long-term solutions. We should not be content to expand the courts' responsibility as primary dispensers of mental health care. This is clearly the most expensive and least effective way to solve the problem. Virtually all accused coming in to mental health courts have had previous contact with the civil mental health care system. However, for whatever reason, that system failed to adequately address the accused's needs. The typical accused comes to court in a very poor state of mental health, totally disconnected from society. When they eventually leave the court they are, for the most part, mentally stable and 'reconnected'. Ultimately, the solution should be found in an overhaul of the civil mental health care system so that mentally disordered individuals needs are met *before* they attract the attention of the criminal justice system rather than after.

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at the Faculty of Law at the University of Toronto. Presently, he is the Alternate Chairman of the Ontario and Nunavut Review Boards. His major research interests are competency and criminal responsibility. His recent books include: *Mental Disorder and the Law: A Primer for Legal and Mental Health Professionals* (2006, with H. Bloom); *Mental Health Courts: Decriminalizing the Mentally Ill* (2007, with H. Bloom and M. Heerema); *Annotated Mental Health Statutes* (2007); and *The Lunatic and the Lords* (2007) [all published by Irwin Law / www.irwinlaw.com].

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[1] Schneider RD. A Statistical Survey of Provincial and Territorial Review Boards, Federal Department of Justice: Ottawa, Canada, 2000.

[2] Kaplan A. Mental Health Courts Reduce Incarceration, Save Money. Psychiatric Times 2007, 24(8): 1 – 3.

COURT SUPPORT SERVICES: FROM CRISIS TO JOURNEY TOWARDS RECOVERY

Rachel Vance*

Joseph,[1] *a 19-year-old man, was placed in custody after being charged with causing a disturbance and uttering threats. Joseph had been standing in front of a store screaming at people passing by when the police were called by the store owner. When the officers attempted to speak with Joseph, he threatened to punch one of them. Six months before his arrest, Joseph began to behave strangely. He was seen talking to the ceiling and laughing to himself. Shortly after this, he left his family home after having a fight with his brother. Joseph lived in various shelters in Toronto, never staying in any one shelter for very long. He would visit his family occasionally and ask his mother for money. His mother described him as acting bizarrely: Joseph believed he was God and that he could heal people with his bare hands. She was also concerned for his safety as the last time she had seen him he had cuts on his forearm. Joseph did not have a diagnosis and refused to see a doctor.*

The Mental Health Court Support Program assists people who are experiencing serious mental health issues and have come in conflict with the law. Many of these individuals have been charged with minor criminal offenses, during a time when they are experiencing severe symptoms of mental illness. In some cases, the individuals have just begun to experience mental health issues and have not been connected to services. Others have had a diagnosis for decades and have, for one reason or another, become unwell.

The Program offers emotional support for individuals as they proceed through the court process. The Program offers a range of services, including: emotional support and advocacy; linkages to community services, such as crisis and long term housing; psychiatry; case management; legal services; immigration services; and educational and vocational programs. The goal of this Program is to support people on their path to recovery and help them reacquire a level of stability in their lives. Mental health and court support services in Toronto are provided by COTA Health, Canadian Mental Health Association, Toronto and Community Resource Connections of Toronto.

The Court Support Program arose from the realization that there is a large population of people with mental health issues who are in conflict with the criminal justice system. Crown counsels may offer mental health diversion to people who have been accused of minor criminal offenses during a time when they are mentally unwell. Mental health diversion allows the individual to be steered away from the standard court process and gain access to needed services. If the person consents to this process and achieves a level of stability by accepting treatment and support, the likelihood of their being in conflict with the criminal justice system in the future will decrease. Mental health diversion allows the individual to be steered away from the negative ramifications of having a criminal record and can result in the withdrawal or staying of all charges. The Crown attorney recognizes that there is a link between the person's mental health issues and the charges and that the individual should receive treatment instead punishment.

Joseph was referred to the Court Support Program by the duty counsel at the court. During a conversation with the court support worker, Joseph stated he didn't think that he was "crazy" but that he was feeling depressed. He was willing to see a psychiatrist and a counsellor because he wanted to talk to someone. He also wanted help finding a place to live. Joseph and his worker developed a plan that included arranging temporary housing and referrals for psychiatry and counselling. Joseph agreed to stay in a short- term residential bed program for 30 days and he was released from custody. Within a few days, Joseph worked with his court support worker and referrals were completed for psychiatry and counselling. The worker also helped Joseph link to a case manager who would be able to meet with him weekly and assist him in finding long-term housing. At Joseph's request, the worker contacted his mother who came to court to *support her son. The psychiatrist diagnosed Joseph with schizophrenia and he started taking medication. Joseph's lawyer and the court support worker spoke to the Crown to discuss Joseph's situation and the Crown agreed that Joseph would be given a mental health diversion if he was able to continue with his treatment plan and maintain a level of stability for six months. Joseph agreed to this and with the support of his family and the case manager, he saw his psychiatrist monthly, maintained biweekly appointments with his counsellor and continued to take his medication. Joseph worked with the case manager and was able to secure long-term housing. He also returned to school part-time and started to work towards completing his high school diploma. After six months of following through with the plan, Joseph was given a mental health diversion from the Crown and all of his criminal charges were withdrawn.*

Stories such as Joseph's demonstrate that the Court Support Program can transform a negative experience – being arrested and charged – into a turning point that could set an individual on the journey towards recovery. This story also illustrates that a collaborative effort from the courts, mental health organizations, psychiatrists, doctors, supportive housing providers and community support agencies is vital in order to provide effective support to people like Joseph.

However, it is important to remember that individuals like Joseph enter the Court Support Program due to a crisis situation that resulted in criminal charges. People with mental health issues would be better served if they could be offered the assistance and support they need before they reach a crisis. Education and collaboration are tools that can be utilized to assist our community in accomplishing this goal. By increasing the community's awareness of mental health issues and the stigma and discrimination that coexists with it, the community will be able to develop a greater understanding of the barriers and challenges that exist for people with mental health issues. Education is also needed to inform members of the community (Crown attorneys, police, defense lawyers, judges, probation officers, psychiatrists, social workers, family members, consumer-survivors, hospital staff and all other service providers) of the services that currently exist in the community and how to access them. All of these members need to develop a collaborative system to increase communication and reduce the barriers and gaps in treatment that lead to people falling through the cracks. Finally, there continues to be a significant need for resources such as long-term psychiatrists and case managers, multicultural and multilingual outreach workers, crisis and long-term housing opportunities and funding for inpatient psychiatric treatment in community hospitals. By improving the community's level of understanding and awareness of mental health issues, improving access to current resources and by securing additional resources, people with mental health issues can be assisted and supported successfully prior to going through the traumatic experience of having contact with the criminal justice system.

*Rachel Vance is a Court Support Worker with COTA Health.

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[1] Name has been changed to protect this individual's identity.

TORONTO'S 102 COURT: AN EXPERIMENT IN ACCIDENTAL POLICY

Lora Patton*

In 1998, one Toronto court crafted a unique response to what was seen as a crisis in the courts and developed a grass-roots strategy to address the needs of persons with mental health differences while also making the court process more efficient. Toronto's Mental Health Court (TMHC), also referred to as "102 Court," opened its doors at the Old City Hall's provincial court with the co-operation of frontline court and mental health workers.

Although there are a number of positive effects of the court, the "accidental" policy implications have also been significant, creating critical issues in the broader policy context. Unintended results have added to pressures in the overarching system of policy and imposing contradictory concepts into an already fragile system. Although one of the primary stated goals of the court is to decriminalize persons with mental illness, the actual result may be quite the opposite as more people are charged and funnelled to mental health diversion. Rigid concepts from the medical model, which includes pharmaceutical treatment, have become ingrained in the criminal justice system, forcing out the client-centred elements of "recovery" that are embraced by the civil sector. Perhaps most critically, funds are forced into the forensic system to meet the immediate needs of the court, shifting money to the forensic system rather than the preventative and voluntary civil mental health sector.

Understanding TMHC in the Policy Context

Mental Health Diversion as Decriminalization

One of the key goals of the TMHC is to decriminalize persons whose perceived illness, symptoms or medication side effects lead to arrest, detention and prosecution. Rather than proceeding with trials, mental health diversion may be implemented after the charge is laid to allow the Crown to withdraw charges against an accused person on the condition that the accused complies with a number of conditions. Post-charge diversion is a worthwhile goal and helps to maintain the efficiency of the court. However, to suggest that diversion at the pre-trial stage allows for decriminalization fails to acknowledge the criminalization that has already occurred. By the time a Crown attorney may offer mental health diversion, the accused person has already been involved with the police and charged, given a police record, likely held in pre-trial custody[1] and subjected to several returns to the court.

Even if the TMHC reduces the amount of time spent in jail by ensuring more timely, on-site assessments, police remain much more likely to take an accused with apparent mental health issues to jail than to hospital. Although the *Mental Health Act* permits officers to take a person directly to hospital,[2] on-going complications in admitting persons to hospital make the police understandably reluctant. Not only are they faced with long delays in many emergency rooms, the legal test for involuntary admission does not always conform to the officer's belief of the need for hospitalization. Police frustration when individuals are released rather than placed on an application for psychiatric assessment leads to more resistance to utilize hospitals. A shortage of civil beds further exacerbates the problem. Unfortunately, as raised below, the civil bed shortage may, in part, result from the pressures placed on the system by the forensic system, leading to a circular problem.

The availability of mental health diversion may actually lead to increased charges against persons with mental illness. Often, the police are faced with situations where a person's symptomatic behaviour may or may not be labelled criminal. Consider, for example, the situation where a person is behaving "strangely" in a coffee shop, perhaps annoying or frightening customers. Certainly stigma and discrimination associated with mental illness, noted as significant in the provincial task force reports,[3] accounts for the increased likelihood that the behaviour will be determined to be "causing a disturbance," "uttering threats" or another criminal offence. Police may be less reluctant to lay a charge for a medical issue if the charge was seen as more serious within the criminal system. Instead, mental health diversion was not viewed as an easy out or "in the best interests" of the accused.

Critically, the TMHC may be seen as a panacea, preventing action on more preventative actions such as reducing stigma and discrimination, increasing early access to services and even pre-charge diversion programs. Very recently, pre-charge diversion programs have started in Toronto, the best-utilized being Sound Times,[4] a consumer-based drop-in centre. At Sound Times, the police can assist a person in meeting with peer counsellors and other services instead of laying charges. Preventative programs and pre-charge diversion are recommended in all policy reports – including the review of the TMHC.

The Medical Model over the Recovery Philosophy

Despite the consistent move to "client-centred care" and the recovery philosophy in provincial policy, the TMHC operates on older assumptions based on the medical model of mental illness. The accused, rather than being seen as a person who is dealing with mental health difference, is only seen as the illness. The illness is seen to have caused the offence. The illness has to be "cured" through efficient means, generally medication.

Medication plays a key role in mental health diversion. Although treatment cannot be ordered by the criminal court except in very narrow circumstances,[5] mental health diversion relies on the "consent" of the accused person to enforce compliance. Where a person refuses medication, they may be ineligible for diversion and, therefore, subject to continued detention or worry pending a trial. Under the *Health Care Consent Act*, consent to any treatment requires voluntariness.[6] Regardless, the recovery philosophy requires that the individual determine his or her options for treatment, potentially rejecting medications and traditional medical interventions. Seemingly forced treatment may discourage the accused from seeking future treatment.

Mental health diversion is inconsistent with the individualized approach. In addition to medical interventions, mental health diversion offers some other supports. For example, mental health workers will often assist in finding housing; however, given the problematic housing situation in Toronto, a "housed" client often means living in a shelter.

Regardless of the treatment or supports provided by mental health diversion, the accused person is "medicalized" – seen as the illness and the crime. In 1975, the Law Reform Commission had called for caution in assuming mental illness should be equated with violence or lawlessness, yet the mental health diversion program creates long-term surveillance of the accused person through months of supervised compliance with diversion.[7] Increased surveillance obviously heightens the risk of failure, as anyone subjected to constant review may be "found out" as inconsistently following rules than a person with more privacy. Further, the existence of mental illness is seen as a cause of the alleged offence. As a result, treatment for mental illness is assumed – rather than the less restrictive diversion processes that are available to other accused persons.

Forced Funding to the Forensic System

While some of the other problems associated with TMHC, outlined above, may be overcome with the balance of a robust civil, voluntary mental health system, the pressures placed on the mental health system as a whole threaten the availability of the civil system. Following the *R. v. Hussein*[8] decision, the Ministry of Health and Long-Term Care has taken a number of steps to increase the availability of assessment beds. Cost is therefore shifted, artificially, due to demand rather than systemically in response to policy, to the forensic system. The higher cost of forensic beds means that costs are transferred out of the mental health funding pool at more than a one-to-one basis, further penalizing the civil system.

Beds are not the only cost consequence of TMHC policies: community supports are also prioritized for accused persons being placed in mental health diversion, creating a shortage for those who are trying to access services outside of the criminal system.

Conclusion

A number of benefits arise from the advent of the specialized TMHC in Toronto. As Justice Richard Schneider noted, the numbers of accused persons with mental disorder in the courts has increased dramatically[9] and the TMHC may ease the burden both on the courts and on the individuals involved. The court was facing a crisis and developed a grass-roots intervention that addressed a single point in the criminal process.

The achievements of the court cannot be denied but also should not be seen as the only means of addressing criminalization, poor access to voluntary services and other fundamental concerns in the broader mental health system. The fact that a number of persons with mental disorder find themselves in the courts may indicate that preventative programs are not properly addressing first evidence of mental illness. Unfortunately, when a person cannot access early service, the only remedy may be continued deterioration until a crisis requires police intervention. Police attitudes and access to mental health services must also be addressed, allowing the police to properly exercise their discretion when faced with a person who appears ill and is in need of supports. As noted in the Regional Task Force Reports, broad stigma/ discrimination elimination efforts are still needed to educate the public about mental illness, and the myths surrounding it.

Not all of the issues to be addressed occur outside the TMHC, however. Just as critical is the reliance on the medical model base of illness and treatment. There is some recognition that social determinants of health have a significant affect on a person's wellbeing as mental health workers will assist an accused in obtaining housing and other services; however, the reliance on pharmaceutical interventions challenges everything we now know about recovery.

Tying all of the various pieces in the system together must be tackled at a high level. The province has ultimate responsibility in ensuring that the various silos – criminal justice, social assistance, housing, corrections, and mental health – regularly communicate and ensure that services are provided in a continuous manner. The lack of communication between stakeholders is identified in every policy document in recent years as a key factor in the failure to co-ordinate services. The failure is critical – the mental health system has one funding block that must be allocated and where one program, such as the TMHC, takes on projects that force funds into the forensic system, that program will have broad systemic impacts.

Despite numerous studies and policy documents, we remain mired in a fixed line between the forensic and civil client group – a distinction that has more to do with the services received than the diagnosis. To achieve a better mental health policy, communication, focus on prevention and recognition of barriers all must improve. Otherwise, other programs will manage crises independently, like the TMHC, and create further system pressure.

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1 Pre-trial custody is increased for persons with apparent mental illness as they are less likely to meet the elements for release.

2 R.S.O. 1990, c. M.7, s.16.

3 See, for example: MacFarlane et al. (September 2002), *A Review of Mental Health Services in Toronto Courts: Final Report*; Ministry of Health and Long-Term Care: www.health.gov.on.ca/english/public/pub/mental/pdf/MOH-op.pdf; Ministry of Health and Long-Term Care, *Themes And Recommendations For Mental Health Reform In Ontario*: www.health.gov.on.ca/english/providers/pub/mhitf/provincial_forum/provincial_forum.pdf; Forensic Mental Health Services Expert Advisory Panel for the Ministry of Health and Long-Term Care (December 2002), *Assessment, Treatment, and Community Reintegration of the Mentally Disordered Offender: Final Report*: www.health.gov.on.ca/english/providers/pub/mhitf/forensic_panel/forensic_panel.html.

4 See website: www.soundtimes.com/.

5 Treatment orders can be made by the court only where an accused is unfit, where treatment is likely to make the person fit and where the hospital consents to provide that treatment. Sections 672.58 through 672.672.63 of the *Criminal Code*, R.S., 1985, c. C-46 outline the procedures for treatment order applications.

6 S.O. 1996, c. 2, Sched. A, s.11.

7 Law Reform Commission of Canada, *The Criminal Process and Mental Disorder*, Working Paper 14, 1975 as discussed in Pilon, M

"Mental Disorder and Canadian Criminal Law (22 Jan 2002), online at: http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/EB/prb9922-e.htm#.

8 [2004] O.J. No. 4594 (QL) (Sup. Ct. Jus.).

9 Schneider, R.D., *Statistical Survey of Provincial and Territorial Review Boards* (Ottawa: Department of Justice, 2000) and Schneider, R. (December, 1998) "Mentally Disorder in the Courts." *Criminal Lawyers Association Newsletter*.

ROLE AND FUNCTION OF THE PROVINCIAL HUMAN SERVICES AND JUSTICE COORDINATING COMMITTEE

Vicky Huehn*

Introduction

In June 1997, the Ontario government's policy framework for people with clinical needs who come in conflict with the law, *A Provincial Strategy to Coordinate Human Services and Criminal Justice Systems in Ontario*, was approved. Subsequently, a number of pilot sites around the province were initiated to create local human service and justice coordination committees.

These groups came together based on a common need to maximize their abilities to fund planning of services without any additional funding. They moved forward as best as possible without any further direction from the government.

Several years later, in 2002, the provincial strategy was revived as the report of the Forensic Mental Health Services Expert Advisory Panel entitled, *Assessment, Treatment and Community Reintegration of the Mentally Disordered Offender*, recommended that:

> The four partner Ministries (Ministry of Health and Long-Term Care, Ministry of Community, Family and Children's Services, Ministry of Public Safety and Security, and Ministry of the Attorney General), with the Ministry of Health and Long-Term Care being the lead Ministry, equally endorse and fund the establishment of local and regional forensic coordinating committees, a key mechanism as per the inter-ministerial report, *A Provincial Strategy to Coordinate Human Services and Criminal Justice System in Ontario* (Human Services and Justice Coordination Project, 1997).
>
> It is further recommended that a formal commitment be made by each of the four Ministries to recreate the Provincial Coordinating Committee to provide support and oversee the work of the Human Services and Justice Coordinating Committees throughout the Province. Local and Regional Human Services and Justice Coordinating Committees must liaise with the Ministry of Health and Long-Term Care as the lead Ministry.

Local Human Services and Justice Coordination Committees

The established Human Services and Justice Coordinating Committees (HSJCCs) were renewed and new ones as required were created throughout the province. The goal of HSJCCs are to respond to a recognized need to coordinate resources and services and plan more effectively for people who are in conflict with the law. Priority consideration is given to people with a serious mental illness, developmental disability, acquired brain injury, drug and alcohol addictions and/or fetal alcohol syndrome. The committees are a cooperative effort of the Ministries of the Attorney General, Community and Social Services, Children and Youth Services, Health and Long-term Care, and Community Safety and Correctional Services.

The two primary areas of emphasis for the committees are:

1. To provide a planning table to bring together service providers to find solutions to the problem of the criminalization of people with defined unique needs; and
2. To develop a model of shared responsibility and accountability in dealing with this group of individuals at points of intersection with the justice system.

Regional Human Services and Justice Coordination Committees

In addition to the local committees, regional committees have been established to coordinate communication and service integration planning between health, criminal justice and developmental service organizations within specific regions.

While the local groups focus on specific service and planning issues, regional groups offer broader based system planning for their geographical area.

Provincial Human Services and Justice Coordination Committee

The Provincial HSJCC provides leadership and supports the regional and local groups to fulfill their mandate to assist people who come into contact with the justice system and who have needs that are appropriate to be met by one of more of the provincial human services systems.

Its work includes identifying both issues and solutions to systemic problems and policy issues. Knowledge exchange is encouraged through participation in a provincial website, conferences and other outreach activities. Meetings are held a minimum of quarterly throughout the year and the work plan undergoes revisions on an annual basis.

The Provincial HSJCC membership consists of one designate from each of the funded Regional HSJCCs with one designate elected annually by the membership as the Chair. Ex-officio representatives include colleagues from the Ministry of Health and Long-Term Care, Ministry of Community Safety and Correctional Services, Ministry of Children and Youth Services, Ministry of Community and Social Services and Ministry of the Attorney General, as well as other groups such as Corrections Canada and the Specialized Care Networks of Ontario.

More information about HSJCCs can be found at www.hsjcc.on.ca.

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[*] Vicky Huehn is the Chair of the Provincial Human Services and Justice Committee, as well as the Executive Director of Frontenac Community Mental Health Services.

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VICTIM IMPACT STATEMENTS AND THE NCR ACCUSED

Michael Feindel[*†]

> *The age old struggle of civilization has been to persuade people not to take justice into their own hands but rather to let their vengeance and righteous indignation be wrought by the law. Western civilization had by the Middle Ages succeeded in substituting private prosecutions for blood feuds. The next step was to replace private prosecution with public prosecution, while asking the victim to forgo whatever satisfaction he might derive from personally prosecuting his transgressor and settling for the more intangible satisfaction of knowing that justice would be done. Now, the modern criminal justice system operates in an age of computers and instant telecommunications, disposing of large numbers of cases without trial and without bothering to give the victim even the minimal satisfaction of knowing what happened to his case and why.*
>
> *— W. MacDonald, "Towards a Return of the Victim" (1976)*

There is little to suggest that MacDonald was being unfair in his description of the diminished role played by victims in the criminal justice system at the time of his writing. It would be another dozen years before Canadian law would try to reverse this trend by introducing legislation in 1988 that gave trial judges the discretion to allow "victim impact statements" to be filed at criminal sentencing hearings. Eight years after that, and likely in response to a less than overwhelming implementation of the new procedure, the section was amended to *require* judges to admit victim impact statements.

Until 1999, victim impact statements were permitted only in cases involving convictions. In cases involving victims of mentally disordered accused, where the accused is not convicted but rather is subject to the "special verdict" of "not criminally responsible on account of mental disorder" ("NCR"), the *Criminal Code*[1] did not provide for the victim an opportunity to file a statement.

NCR accused come under the jurisdiction of Part XX.1 of the *Criminal Code*. This Part sets out a comprehensive procedure for assessing and supervising an accused once he or she has been found NCR. In particular, the Part provides for regular hearings to be conducted by provincially-constituted Review Boards whose task is to determine whether the accused poses a significant threat to public safety and, if so, what order would manage that risk in a way that is least intrusive to the liberties of the accused.

In 1999, Parliament amended Part XX.1 to require the court or Review Board, at the *initial* hearing after an NCR verdict, to canvass whether or not the victim wished to file a statement. This preliminary legislative step toward victim participation was expanded upon in 2006, when Parliament introduced a number of additional changes pertaining to victims. The new provisions permit the filing of impact statements at *every* review hearing and require the Board under certain circumstances to give "notice" to victims when there is a recommendation to discharge the accused into the community either conditionally or absolutely.

Notwithstanding the changes to the law, the role victims ought to play in relation to NCR cases is a live question that participants in the Review Board hearing process continue to grapple with. The debate often centers on the value and relevance of having victims appear and read their statements into the record, often with understandable emotion, at hearings whose primary focus is to assess ongoing risk. Some argue that there is no *moral nexus* between the accused and the NCR crime and that, therefore, a "statement" by the victim as to the injury they suffered, as tragic as that injury may be, has little or no relevance in the context of a Review Board hearing and may even promote false expectations on the part of the victim.

The law, in my view, suggests a different position. The NCR verdict is commonly referred to as a "special verdict" and while little may turn on that technical label, it nevertheless names a difference that merits our attention. The "special verdict" does not stand "in between" guilty and not guilty. There is no "in between" to that choice: in our criminal justice system, "maybe" simply counts as not guilty. The finding of NCR stands outside of this dichotomy; it neither condemns nor absolves. I would suggest, rather, that it names an entirely different set of problems that call for an approach that deviates substantially from the adversarial standard of the criminal courts.

The verdict of NCR tends to be viewed as "exculpatory" (historically, mental illness gave rise to an "insanity *defence*") because the accused is found to be "*not* criminally *responsible*." At the same time, however, this absence of responsibility is precisely what grounds the State's intervention or criminal jurisdiction over the accused. The accused was not in control at the time of the "index offence" (the NCR crime); therefore, society intervenes in an effort to manage this dyscontrol where it believes there is a risk further criminal behaviour would occur if it did not. As Binnie J. illustrated in *R. v. Owen*, [2003]:

> The respondent says if he were to re-offend while on drugs, he would be subject, like anyone else, to the strictures of the *Criminal Code*. But he is not like anyone else. He is a NCR detainee whose drug abuse is linked to a demonstrated propensity for violence, including murder, and *Part XX.1 of the Criminal Code is designed to take measures to protect the public's safety before violence occurs, not (as in the ordinary case) to punish the offender afterwards.*[2] [Emphasis added]

The victim of the index offence is by definition afflicted with the same concern respecting the accused's propensity for recidivism as is the State. The injury he or she suffered will not be ultimately redressed through the conventional criminal justice system. In other words, victims of NCR accused cannot look to "rehabilitation" or "deterrence" for future safety or wish the accused see the "error of his or her ways." The very circumstances that legitimate an NCR verdict will most often preclude such expectations of "justice being done." The only "justice" possible is that of which *Owen* speaks: the justice that seeks to prevent "this" from ever happening again.

The "nexus," then, between the victim of the NCR offence and the NCR offender is the accused's unmanaged risk. Both the victim and the Review Board therefore, at least in theory, share the same end of "treatment and stabilization" of the accused. Moreover, a clear and relevant touchstone for the assessment of risk is going to be found in the seriousness and scope of the index offence. The index offence is a measure of what could happen if the accused were not treated and stabilized.

In this context, a victim impact statement can serve a number of relevant purposes: the extent to which it can provide an additional perspective to the representation of the nature and scope of the index offence is in my view probative in assessing significant risk. A victim impact statement may also have the potential to identify concerns that could possibly be addressed by the conditions of a disposition where the Board sees fit. Given the *de novo* aspect of Review Board hearings, it makes sense that Parliament permitted the filing of a statement on a recurrent basis as necessary.

Valid concerns can still be raised with respect to the introduction of victim impact statements to Review Board hearings. One objection is rooted in the view that the victim, consciously or unconsciously, really views the accused as *guilty*. In my experience, victims not infrequently view the "special verdict" as a failure of justice. In their eyes, the accused was *responsible* for the offence; the crime flowed directly from his or her actions. The accused *is* to blame. It is difficult for some victims to come to grips with these feelings within the context a verdict of NCR.

The victim's perplexity can sometimes result in impact statements that are critical of the NCR finding or express sentiments at odds with the purposes of Part XX.1. The question arises whether such statements should be admitted at the hearing or whether, as some Boards have done, the offending material should be "edited out." However, impact statements at Board hearings are not being submitted in relation to a criminal sentencing. The extent of their effect on the tribunal is limited to the information they provide that may contribute to the assessment that the Board is mandated to undertake. Editing therefore seems redundant and unnecessary.

A more complicated and difficult question to assess is the effect that victim impact statements might have on the accused and whether in some cases such an effect could be counter-therapeutic. Much depends on the analysis of the specific circumstances of the case but the Board is equipped to cope with that situation in a number of ways, including accepting the statement in written format in lieu of it being read in to the record.

Review Boards are boards of inquiry. The recent amendments enhancing victim participation recognize that the impact of the index offence on members of the public can be relevant to that inquiry. The nexus of "unmanaged risk" between the victim and the NCR accused, otherwise referred to as the "index offence," is a touchstone for the Board's ongoing assessment of risk and its commitment to prevent recidivism. The absence of a moral nexus underscores the rationale for the intervention by the Board to manage that risk in the hopes that "justice" can be achieved by preventing "this" from ever happening again.

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[†] I should make it clear that while in the employ of the Ministry of the Attorney General, the views and opinions expressed herein are my own and not those of the Ministry.

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1 R.S., 1985, c. C-46.
2 1 S.C.R. 779, 174 C.C.C. (3d) 1 ["Owen"] at para. 65.

FOUNDATIONS OF MENTAL HEALTH LEGISLATION IN CANADA

Daniel J. Brodsky[*]

For centuries lawmakers have struggled to define the methodology of, and the justifications for, social control of individuals who may not conform to community mores. In particular, the historical origin of the present day legislative scheme to protect the public from mentally disordered individuals who are said pose a threat to the safety of others is ancient and evolving. It can be traced back through the writings of Sir Matthew Hale in the seventeenth century on the special verdict of "acquittal and enlargement," Sir Edward Coke in the sixteenth century and Brackton in the thirteenth century with rudimentary beginnings even earlier to Aristotle's fourth century bipartite division of knowing and acting. Prior to the invention of medicine, psychiatry or psychology, it was commonly believed that the only way to protect society was to keep mentally disordered offenders from places where they could cause harm.[1] Efforts to come to grips with the problem included the enactment of civil statutes such as the *Vagrancy Act of 1744*, but resort to these laws was informal and irregular.[2] At common law, there was little difference if insanity was raised before a criminal trial or as a defence because it was the question of "dangerousness" itself (not civil versus criminal procedure) that informed detention status of the prisoner, as well as readiness for release even if the cause was unknown. Setting the stage for a dramatic moment in history was the fact that no criminal sanction similar to the vagrancy laws were available to restrain insane acquittees since the accused would "go at large" after a verdict.[3]

On May 15, 1800, gunfire at Richard Sheridan's Theatre Royal in Drury Lane suddenly brought this problem to the attention of the public.[4] That evening, as King George III was entering the playhouse and advancing to take his seat for *Le Nozza di Figaro*, James Hadfield discharged a horse pistol at the King.[5] Mr. Hadfield believed he was commissioned by God to prevent the end of the world by sacrificing his life for the salvation of all mankind. He could not commit suicide (a moral crime), but he knew that he would surely be executed for the crime of attempted regicide. Mr. Hadfield was arrested and charged with high treason.[6]

Mr. Hadfield was tried on June 26, 1800. Attorney General John Milford[7] appeared for the Crown and Thomas Erskine was assigned for the defence.[8] A plea in the usual form – not guilty – was recorded. Following the close of the Crown's case and only part way through Mr. Hadfield's defence, Lord Kenyon, the Chief Justice, turned to the Crown in the jury's presence to find out if the defendant's insanity was contested.[9] Attorney General Milford replied that while the Crown knew beforehand that Mr. Hadfield had been discharged from the army on grounds of insanity, the particulars proffered by the defence were "perfectly unknown" beforehand. Lord Kenyon immediately charged the jury on the issue of preventative detention (acquittal and confinement) and the threshold of necessity underscoring that,

> … it is absolutely necessary for the safety of society that he should be properly disposed of, all mercy and humanity being shown to this most unfortunate creature. But for the sake of the community, undoubtedly, he must somehow or other be taken care of, with all the attention and all the relief that can be afforded him ... but at present we can only remand him to the confinement he came from …

The Attorney General explained to the jury that,

> It is laid down in some of the books, that by the common law the judges of every court are competent to direct the confinement of a person under such circumstances.

Counsel for the defence addressed the jury and made the following admission:

> My Lord, we who represent the prisoner … subscribe most heartily to the law as it has been laid down by my learned friend the Attorney General; most undoubtedly the safety of the community requires that this unfortunate man should be taken care of.

Finally, assistant Crown Garrow made the following recommendation:

> Would it not be for the benefit of prosperity, if the jury would state in their verdict the grounds upon which they give it, namely, that they acquit the prisoner of this charge, he appearing to them to have been under the influence of insanity at the time the act was committed? There would be a legal and sufficient reason for his future confinement.

The foreman of the jury delivered its verdict as follows:

> We find the prisoner is not guilty; he being under the influence of insanity at the time the act was committed.

There was no material difference between civil and criminal mental health law before the jury returned a verdict of not guilty by reason of insanity (NGRI) in James Hadfield's case, but that was about to change because Lord Kenyon had already determined that Mr. Hadfield would not "go at large" if he was found not guilty. His Lordship was satisfied that it was essential to protect the public to issue an order for the insane acquittee to be taken to Newgate Prison where he would be interned indefinitely.[10] For a time after the order was executed, a debate raged over its legitimacy since it was generally agreed that Mr. Hadfield should not be punished.[11] Moreover, a foundational pillar of the criminal justice system had been the belief that all people on trial are presumed innocent until proven guilty and they were entitled to hold the prosecution to its high burden of proof. However, proof beyond a reasonable doubt for predicted future crimes was unattainable. On the other hand, many people were concerned for their own safety if Mr. Hadfield were permitted to go at large to walk the streets.[12]

Parliament responded with surprising dispatch and passed the *Criminal Lunatics Act of 1800* empowering the courts to order the detention in safe custody of insane persons charged with offences. For Mr. Hadfield, the detention was for the rest of his natural life. The enactment legalized the automatic detention of those who were acquitted on the grounds of insanity until "His Majesty's pleasure to be known."[13]

Henry Pope in his treatise on the law and practise of lunacy articulated the twin animating objectives of the new law as follows:

> It is to the interest of public safety that society should itself be protected against the insane. Possessed of physical force without a regulating mind and subject to the natural instincts untutored by discipline and uncontrolled by fear of punishment, some classes of the insane threaten continual danger to those they are brought into contact. The very motiveless of acts is an additional element of peril. Hence again the duty and right of the state, for its own sake as well as that for the insane, to exercise peculiar powers of seclusion and control.
>
> Nor is it merely against others that this protection is needed or conferred. From the same primary principle of the sanctity of human life, and the paramount importance to society of maintaining that principle in its integrity, the state is concerned to protect the insane against themselves. Hence at once the duty and the right to exercise coercion and impose restraint.[14]

The choice to raise the insanity defence was not discretion to be lightly exercised.[15] No longer was a defendant found not guilty on the grounds of insanity (NGRI) entitled to an unencumbered acquittal.[16] Insanity became the special verdict linked with automatic indefinite confinement.[17] The NGRI accused was designated a "criminal lunatic" to be detained for an indeterminate period and the hope of successful rehabilitative intervention was not a prerequisite of admission to this new regime for the safe custody of insane persons because it was presumed that the NGRI accused lunatic was beyond rehabilitation.[18] Moreover, as it amounted to an acquittal, there was no right of appeal.[19]

While medicine in general had its renaissance in the sixteenth century, progress in psychiatry lagged behind. The NGRI lunatics were treated, not as a sick patients, but like wild animals (beasts) or criminals and it is not uncommon to read or hear accounts of restriction by chain and manacle; incarceration in dank, sunless dungeons that were seldom visited by physicians. Since the insane offender was originally considered to be beyond rehabilitation, it was typical for little or no treatment to be provided and detention was indefinite. While rehabilitation was always hoped for, unfortunately treatment proved to be abortive until well into the nineteenth century and truly effective therapeutic interventions were not developed until the twentieth century. Indeed, it was well into the late 1800s before mental health care workers began to invest their time and energies into this segregated population of offender. Howden J. observed that,[20]

> As a result of this rather superior expression of benevolent concern for a fellow "creature," counsel for Mr. Hadfield and the Attorney-General, in addition to Lord Kenyon, agreed he should not be released because of his potential dangerousness or risk to the public. From this situation, the asylum approach to dealing with the mentally disordered in the criminal justice system was born in the *Criminal Lunatics Act*. It provided that for a person acquitted of certain major crimes by reason of insanity, the court would order him or her to be kept in custody, "in such place and such manner as the court shall deem fit, until His Majesty's pleasure is known," and the King was authorized to make a corresponding order for safe custody until his pleasure was known. However, this relief was required only where "it may be dangerous to permit persons so acquitted to go at large."[21]

The basic ideas of separate detention, danger to society, and insanity remain still in the new detention review system, though the variety and methods of treatment which exist today in the post-Freud and post- Jung era of psychiatric and psychological sciences have advanced and differ greatly from 200 years ago when detention overrode other concerns, at least in law. As well, to some extent it is apparent from the present system, and the former LGW system as it was before *Swain*, that those basic ideas not only remain alive but the notion of relating mental disorder to threat to society has become ingrained in the criminal law as a general perception.

On January 20, 1843, a pistol shot in the parish of Saint Martin in the Fields, in the County of Middlesex, brought the problem to the attention of the public once more. That day, Daniel McNaughton shot Edward Drummond, a civil servant and Personal Secretary to the British Prime Minister Robert Peel, mistaking Drummond for Peel, the intended mark. Mr. McNaughton saw a figure that he believed to be the Prime Minister from the rear approaching Downing Street.[22] He fired a single shot into the back of the person he believed to be Prime Minister Peel. After the shooting Mr. Drummond walked to his brother's house nearby where he passed away five days later despite the medical attention he received.[23]

Mr. McNaughton entered a plea of not guilty and was tried for murder on March 3 and 4, 1843. Solicitor General William Webb Follett[24] appeared for the Crown and Alexander Cockburn, Q.C. led the defence.[25] Following the close of the case for the defence, the Chief Justice asked the Crown if Mr. McNaughton's insanity was contested and the Solicitor General answered that,

> … I feel that I should not be properly discharging my duty to the Crown and to the public if I asked you to give your verdict in this case against the prisoner.[26]

The jury verdict in the trial of Mr. McNaughton was NGRI. Consequently, Chief Justice Tindal directed the gaoler to keep the prisoner in safe custody till Her Majesty's pleasure be known. He was subsequently remanded to Bethlem Royal Hospital where he lived for 20 years before his transfer to the Broadmoor Institution for the Criminally Insane, where he died in 1865.

The attempted assassination of Prime Minister Peel prompted Lord Broughm to initiate a debate on the NGRI verdict and the nature and extent of the unsoundness of mind which would excuse the commission of a crime.[27] The House of Lords debated the matter on March 6 and 13, 1843 before determining it would take the opinion of the judges on the law governing such cases. Accordingly, on June 19, 1843, fifteen judges of the common law courts, including Lord Chief Justice Tindal,[28] attended the House of Lords to answer a series of questions. The questions were put to the commissioners orally and their answers founded, among other things, the specific test to be applied by a trier of fact in an insanity case that became known as the M'Naghten Rule.[29] The case is significant as well because it underscores the long process of attempting to integrate and apply the growing body of knowledge in the mental health field to the criminally insane.[30] The goal was and always has been risk reduction.[31]

The provisions of the *Criminal Lunatics Act of 1800* were incorporated into the draft British *Criminal Code*[32] which was never enacted but which was later adopted in Canada within our first *Criminal Code* that came into force on July 1, 1893.[33] Section 736 of the *Criminal Code (1893)* provided for the strict custody of Insane Acquittees in such places and in such a manner at the pleasure of the Lieutenant-Governor and the enactments remained virtually unchanged in form until the proclamation of Bill C-30 on February 5, 1992.[34]

After a contemporary criminal trial, a not criminally responsible (NCR) Accused is not free to "go at large." Rather he or she is removed from the mainstream of the criminal justice system and faces indefinite detention and a detention review by a tribunal that must be satisfied that the NCR Accused does not pose a significant risk to public safety before release is a possibility.[35] Today Part XX.1 of the *Criminal Code* guides the approach to dealing with offenders who are not criminally responsible for their behaviour or who may be unfit to stand trial:

> When insanity provides an exculpatory defence, the actor remains very much the concern of the criminal law. The insanity rules identify special mental conditions under which persons cannot be expected to ensure that their conduct conforms to the requirements of law; and therefore the general law of criminal culpability is unsuited. The actor is formally acquitted because mental impairment has made the standard penal sanctions inappropriate. Alternative coercive

> measures may, however, be taken because of the potential dangerousness of the condition … Under the old provisions of the Criminal Code based on the common law rule, the accused relieved of criminal responsibility by reason of insanity was referred to as an NCRMD "acquittee" ... Under Part XX.1, by contrast, the NCRMD offender is not acquitted. He or she is simply found to be not criminally responsible. People who fall within the scope of Part XX.1 are more appropriately referred to as simply NCRMD accused.[36]

Part XX.1 of the *Criminal Code* supplements the traditional guilt-innocence dichotomy of the criminal law with a new alternative for the NCR Accused – an alternative of individualized assessment to determine whether the person poses a continuing threat to society coupled with an emphasis on providing rehabilitative opportunities. In this regard, Parliament brings into play the criminal law power to prevent further predicted criminal conduct while acknowledging that the NCR Accused is not morally culpable. Part XX.1 of the *Criminal Code* aims to preserve the autonomy and dignity of the individual without compromising the safety of the public or the person by striking a balance between the protection of the public and the fair rehabilitation of morally blameless offenders.[37] This delicate balance is maintained by ensuring that the State's legal intervention in restricting the liberty of the individual is no greater than necessary.[38]

An NCR verdict is a historical finding that the person on trial suffered from a "disease of the mind" and committed the *actus reus* of an offence. It is not a determination of present or future dangerousness. While it may very well be rational to assume that persons found NCR are dangerous, this assumption will not be true for all NCR Accused. Lamer J. in *R. v. Swain* specifically cautioned:

> [W]hile the assumption that persons found not guilty by reason of insanity pose a threat to society may well be rational. I hasten to add that I recognise that it is not always valid. While past violent conduct and previous mental disorder may indicate a greater possibility of future dangerous conduct, this will not necessarily be so. Furthermore, not every individual found not guilty by reason of insanity will have such a personal history.[39]

The NCR verdict[40] triggers a disposition hearing under Part XX.1 of the *Criminal Code* and an assessment of whether the NCR Accused poses a significant threat to the public.[41] The "disposition" can be an absolute or conditional discharge, detention in a hospital, and/or treatment. The trial judge may then make a disposition order pertaining to the NCR Accused or defer the disposition decision to a Review Board. After the initial disposition order is issued, the NCR Accused comes under the jurisdiction of a provincial Review Board where disposition orders other than absolute discharges are reviewed. From this time forward, the NCR Accused's liberty restrictions are not supposed to be that dissimilar to that of the incapacitated civil detainee that is involuntarily committed under civil statutes until such time as he or she cannot be said to be a significant threat to the safety of the public. Of course, there are very important liberty interests at stake when a Review Board makes a disposition.[42] Such preventative detention is a serious infringement of personal liberty and it must be reasonable and demonstrably justified in the circumstances.[43]

The "twin goals" of our present day legislative scheme are protecting the safety of the public and treating the offender fairly.[44] Giving effect to these laudable goals requires a Review Board to annually review the status of every person in Canada who has been found to be not criminally responsible on account of a mental disorder or unfit to stand trial and grant the disposition that is the least onerous and least restrictive one compatible with the offender's situation, taking into account the four factors enumerated section 672.54 of the *Criminal Code* (public safety, mental condition of the accused, other needs of the accused, and the reintegration of the accused into society). In other words, a Review Board's jurisdiction to do anything other than order an absolute discharge only attaches if a positive finding can be made on evidence before the tribunal that the person poses a significant threat to the safety of the public.[45]

Recently, Justice Linhares De Sousa of the Superior Court of Justice reaffirmed that,

> … the proceedings of the ORB [Ontario Review Board] have a dual purpose as follows:
>
> (a) protecting the safety of the public; and
>
> (b) treating the offender fairly …
>
> Tasked with this dual purpose, the ORB also bears the burden of making a disposition which is "the least onerous and least restrictive to the accused" taking into consideration the following four factors, namely, "the need to protect the public from dangerous persons, the mental condition of the accused, the reintegration of the accused into society and the other needs of the accused" (section 672.54 of the *Criminal Code of Canada*).[46]

Justice De Sousa also observed that,

> Parties may disagree as to the appropriate disposition which should be made. In this case, Mr. Leyshon-Hughes and counsel for the Crown do disagree. Nonetheless, no one party bears the burden of "proving" or establishing risk to the public in any given case. As the Supreme Court of Canada pointed out at

paragraph 54 of its decision,

> The legal and evidentiary burden of establishing that the NCR accused poses a significant threat to public safety and thereby justifying a restrictive disposition always remains with the court or Review Board. If the court or Review Board is uncertain, Part XX.1 provides for the resolution by way of default in favour of the liberty of the individual.

… before a Review Board has jurisdiction to do anything other than order an absolute discharge, they must make a positive finding that the offender "poses a significant threat to the safety of the public."

Finally, De Sousa J. underscored that to discharge its legislative mandate, a Review Board must:

> … exercise all … inquisitorial powers within the context of a hearing during which the NCR Accused is accorded all his constitutional and statutory rights to procedural fairness. … an explanation … is misplaced when it sacrifices procedural fairness in the interests of efficiency…[47]

The law has changed quite substantially since that fateful gunshot on May 15, 1800 but it still has a long, long way to go. I'm looking forward to reading the Psychiatric Patient Advocate Office's Special Report: *Honouring the Past, Shaping the Future – 50 Years of Progress in Mental Health Advocacy and Rights Protection.*

*Daniel J. Brodsky is a criminal defence lawyer who devotes a significant amount of time to activities that advance the rights of mentally disordered individuals in conflict with the law. Daniel has published, lectured and participates regularly as an invited faculty member for the Canadian and American Academy of Psychiatry and the Law. Daniel has championed this cause in many jurisdictions before all levels of court in Ontario, including review boards, inquests and public inquiries, as well as the Federal Court and the Supreme Court of Canada.

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1 Up until a few decades into the nineteenth century, the medical profession knew little about mental disorder and believed insanity to be incurable. The treatments that were attempted, such as those involving leeches to remove 'tainted' blood from the insane, were futile.

2 The *Vagrancy Act of 1744* is the touchstone for present day civil mental health legislation.

3 Nigel Walker, *Crime and Insanity in England* (Edinburgh, 1968) at vol. 1, 84 – 85; George Keeton, *Guilty But Insane* (London, 1961) at 14 – 15; *R. v. LePage*, [1994] O.J. No. 1305 at para. 65; *Winko v. British Columbia (Forensic Psychiatric Institute)*, [1999] 2 S.C.R. 625 at para. 17 – 43; *MacDonald et. al. v. Vapour Canada* [1977] 2 S.C.R. 134; *Starnaman v. MHC-P* (1995), 24 O.R. (3d) 701 (Ont. C.A.).

4 His Majesty was in the company of his son, the Duke of York, Queen Charlotte and the Princesses Augusta, Elizabeth, Mary and Amelia.

5 That Mr. Hadfield 'missed' his target is unclear because it is unknown if the intent was to actually assassinate or just signal the attempt, and then address the King, announcing "God bless your royal highness; I like you very well; you are a good fellow; but this is not the worst that is brewing."

6 *R. v. Hadfield* (1800), 27 St. Tr. 1281 at 1281 – 1283, 1294, 1298 – 1299, 1307 – 1330, 1353-1356.

7 Later Sir John Milford, Speaker of the House of Commons and Lord Chancellor of Ireland.

8 Later Lord Chancellor Erskine.

9 Counsel for the defence indicated that 20 further witnesses had yet to testify.

10 The civil mental health system did not stop James Hadfield on May 15, 1800 and Lord Chief Justice Kenyon was not about to invoke the civil system after the jury verdict was rendered.

11 The insanity acquittal itself was the exercise of compassion because it was seen as cruel to inflict punishment on an insane acquittee.

12 Does this debate persist? Consider the 2002 science fiction film "Minority Report" staring Tom Cruse that was based on a short story of the same name for a pop-culture commentary on the perils of hidden false negatives for society [offenders who are predicted not to recidivate who do re-offend].

13 Larry Gostin (ed.) *Secure Provision, A Review of Special Services for the Mentally Ill and Mentally Handicapped in England and Wales* (London, 1985) at 15; Norman Finkel, *Insanity on Trial* (New York, 1988) at 16; A.J.C. O'Marra, cited in *Hadfield to Swain; The Criminal Code Amendments Dealing With the Mentally Disordered Accused* (1993), 36 Crim. L.Q. 49; Richard Moran, *The Origin of Insanity as a Special Verdict: The Trial For Treason of James Hadfield (1800)*, Law & Society Review, Vol. 19, No. 3, December, 1985, at 601-633; George Keeton, *Guilty But Insane* (London, 1961) at 17 – 61; Nigel Walker, *Crime and Insanity in England* (Edinburgh, 1968) at vol. 1, 15 – 51, 74 – 83; *R. v. LePage*, [1994] O.J. No. 1305 at para. 65 – 66 (S.C.J.).

14 Henry Pope, *A Treatise on the Law and Practise of Lunacy* (2d ed. London, 1890) at 4 – 5, 401 - 402

15 *R. v. Scott* (1993), 87 C.C.C. (3d) 327 (Ont. C.A.), [2004] O.R.B.D. No. 138.

16 In effect, the NGRI verdict is a form of conviction and the LGW is a form of indeterminate sentence.

17 The power to confine was exercised with disinterested indifference. Margaret Hall, Selected Writings of Benjamin Nathan Cardozo (New York, 1938) at 262.

18 Oliver Wendell Holmes, *The Common* Law (Boston, 1881) at 42 – 43, 108 – 109; F.A. Whitlock, *Criminal Responsibility and Mental Illness* (London, 1963) at 44, 52; *R. v Felstead*, [1914] AC 534.

19 There is still no *Criminal Code* provision for a special plea where section 16 is resorted to as a defence in Canadian law.

20 *R. v. LePage*, [1994] O.J. No. 1305 at para. 66 – 68 (SCJ); Roger Smith, *Trial by Medicine: Insanity and Responsibility in Victorian Trials* (1981, Edinburgh).

21 Appellant's factum in *Swain v. R.* p. 43, by C. Ruby, M. Edwardh and M. Code.

22 Mr. McNaughton believed that he was being persecuted by the police, the Church of Rome, the Tories and the Prime Minister and he needed to defend himself.

23 *McNaghten's Case* (1843), 10 Clarke & Finnelly 200; 8 E.R. 718; [1843-60] All E.R. Rep. 229; *sub nom. McNaughton's Case*, 4 St. Tr. N.S. 847; 1 Town. St. Tr. 314; 1 Car. & Kir. 130, n; *sub nom. Insane Criminals*, 8 Scott, N.R. 595, H.L.; 14 Digest (Repl.) 60, 246; *sub nom. M'naghten's Case*, Mews' Dig. i. 349; iv. 1112. S.C.; 1 C. and K. 130; Nigel Walker, *Crime and Insanity in England* (Edinburgh, 1968) at vol. 1, 91; George Keeton, *Guilty But Insane (London, 1961)* at 99 - 101.

24 Later Sir William Webb Follett, Attorney General.

25 Later Lord Chief Justice.

26 *McNaughton's Case*, 4 St. Tr. N.S. 847 at 923 – 926.

27 The reverberation from the shots fired at the Queen during her pregnancy by Edward Oxford brandishing two pistols as she was

being driven up Constitution Hill with her husband, Prince Albert and the NGRI verdict three years earlier, may well have informed the monarch's request of the Law Lords to reconsider the right-wrong test. Mr. Oxford was tried for high treason and found NGRI in July 1840. He was sent to Bethlem Royal Hospital, where he remained until the criminal patients of the institution were transferred to Broadmoor Hospital in 1864. Three years later, he accepted a discharge on the condition that he would leave the country. He left for Australia with dispatch and was never heard of again (*R. v Oxford*, [1840] 4 State Trials (New Series) 498, 9 C. & P. 525, 1 Town. St. Tr. 102; 14 Digest (Repl.) 60, 235).

28 The trial judge who presided over the *McNaughton* case.

29 The murder of Edward Drummond was a mistake; Daniel McNaughton intended to kill the Prime Minister and he knew that what he intended to do was against the law. Accordingly, the law lords would have found Daniel McNaughton to have been guilty but insane.

30 *Atkin Committee on Insanity and Crime* (1923); F.A. Whitlock, *Criminal Responsibility and Mental Illness* (London, 1963) at 20 – 22, 41, 43 – 45; Charles Rosenberg, *The Trial of the Assassin Guiteau: Psychiatry and Law in the Gilded Age* (Chicago, 1968); *M'naghten's Case*, Mews' Dig. i. 349; iv. 1112. S.C.; 1 C. and K. 130.

31 Efforts to empirically validate rehabilitation and management techniques to reduce the risk of future harm (dangerousness) are, however, only of recent origin.

32 *Report of the Royal Commission Appointed to Consider the Law relating to Indictable offences: With an Appendix Containing a Draft Code Embodying the Suggestions of the Commissioners* (London, 1879) at 192; Nigel Walker, *Crime and Insanity in England* (Edinburgh, 1968) at vol. 2, 1 – 17.

33 See ss. 738 - 741 of *The Criminal Code, 1892.*

34 The main part of Bill C-30 formed what is now Part XX.1 of the *Criminal Code,* R.S.C. 1985, c. C-46.

35 Originally, Parliament was under the impression that the *Charter* demanded fixed limits to the criminal law power and stigmatization and Part XX.1 of the *Criminal Code* included capping provisions that were thought to be a finely tuned and well thought out balance between the rights of an NCRMD accused and the protection of the public. Parliament contemplated that the regime for the detention and control of mentally disordered accused persons under Part XX.1 of the *Criminal Code* would be proportional to the gravity of the index offence, and detention would be finite except for the gravest offences, such as murder or high treason. Concerns over post-cap continuing dangerousness caused the notion of proportionality to be abandoned and the unproclaimed capping provisions were subsequently repealed (See *Bill C-10, An Act to amend the Criminal Code (mental disorder) and to make consequential amendments to other Acts*, 1st Sess., 38th Parl., 2004 (assented to 19 May 2005) S.C. 2005, c. 22).

36 *Lingley v. New Brunswick Board of Review* (1973), 13 C.C.C. (2d) 303 (F.C.T.D.) at 308.

37 *Attorney General of Ontario* v. *Grady* (1988), 34 C.R.R. 289 (Ont. H.C.J.); *R. v. Swain,* [1991] 1 S.C.R. 933 at 970-72, 1024-30.

38 *Winko* at para. 17 – 18, 20, 32, 40, 42 - 43, 183 -186; *Starson v. Swayze,* [2003] S.C.C. 32 at para. 6-7, 10, 75, 91, 112.

39 *Swain,* at 1015.

40 The initial finding is made by the judge or jury trying the defendant.

41 Throughout the process, the NCRMD accused is to be treated with dignity and given the maximum liberty compatible with the twin goals of protection of the public and fairness to the NCR Accused.

42 In particular, isolating offenders in secured institutions away from the mainstream of society thereby incapacitating their risk to the community.

43 *Winko* at para. 209; *R. v. Tulikorpi*, [2004] 1 S.C.R. 498 at para. 53.

44 *Winko* at para. 42, 48 – 49; *R. v. Mazzei*, [2006] 1 S.C.R. 326 at paragraph 28; *Penetanguishene Mental Health Centre v. Ontario (A.G.)*, [2004] 1 S.C.R. 498 at paragraphs 51 to 56; *Criminal Code*, section 672.54.

45 *Leyshon-Hughes v. Ontario* (2007), 220 C.C.C. (3d) 121 at para. 15(g), 16 (S.C.J.); *Mazzei v. British Columbia (Adult Forensic Psychiatric Services, Director)* (2006), 206 C.C.C. (3d) 161 at para. 16 (S.C.C.); *R. v. Owen*, [2003] 1 S.C.R. 779 at para. 33-34.

46 *Leyshon-Hughes* at para. 37, 48 – 51, 53, 56 – 57, 62 – 65, 68 - 90.

47 *Leyshon-Hughes* at para. 37, 48 – 51, 53, 56 – 57, 62 – 65, 68 - 90.

AMICUS CURIAE: COURT OF APPEAL

Larissa Ruderman*

In 2005, the Court of Appeal for Ontario launched an *amicus curiae* program for appeal hearings from Ontario Review Board patient disposition decisions. An *amicus curiae* ("*amicus*"), or friend of the court, is a lawyer appointed by the court to assist with an appeal. An *amicus* may be appointed where the patient is unrepresented, regardless of whether the patient is launching an appeal from the Review Board's decision, or responding to one. In the majority of cases, the patient is appealing from an order of the Review Board. An *amicus* can provide the court with information about the facts of the case, applicable legislation, or relevant case law.

The Review Board has jurisdiction over an accused person found not criminally responsible on account of mental disorder or unfit to stand trial. Pursuant to s.672.54 of the *Criminal Code,*[1] the Review Board may direct that an accused person be discharged absolutely where a court rendered a verdict of not criminally responsible on account of mental disorder. Alternatively, the Review Board may direct that the accused person be discharged subject to appropriate conditions, or direct that the accused person be detained in custody in a hospital subject to appropriate conditions. The disposition is subject to annual review.

Any party may appeal against a disposition or placement decision made by the Review Board to the Court of Appeal for Ontario. Because of the annual reviews, patients sometimes launch further appeal from such subsequent dispositions.

When the court receives notice that a party is appealing a decision of the Review Board, the court will contact the Psychiatric Patient Advocate Office program manager designated to deal with matters arising in the psychiatric facility where the patient is being held. The court will inquire whether the patient has counsel of choice, or whether an *amicus* appointment is appropriate. The program manager will contact the patient advocate at the patient's facility, who in turn consults with the patient. If the patient advises that he or she wishes to be represented by counsel who has agreed to accept the retainer, the court may assist in facilitating such representation. If, on the other hand, the patient is unable to retain counsel or is unwilling to be represented by counsel, the patient advocate advises that an *amicus* appointment is appropriate. The court will then contact one of the lawyers on the court's *amicus* roster.

The Court of Appeal developed the *amicus* program with input from the Mental Health Legal Committee, the Criminal Lawyers' Association, and the Ministry of the Attorney General. Funding for the *amicus* lawyers is provided by the Ministry of the Attorney General.

The *amicus* program has greatly improved the Review Board appeal process at the Court of Appeal. The program allows a patient's legal interests to be presented to the court where the patient may be resistant to representation, or where the patient is unable to discern or clearly articulate the merits of the appeal. *Amicus* lawyers are experienced appellate lawyers who deal extensively with mental health issues. Because an *amicus* lawyer is not counsel for the patient, he or she is not obliged to advance arguments as instructed by the patient. The patient is entitled to attend the hearing and make submissions regarding the issues. The *amicus* counsel's function is neither to comment upon nor to undercut such arguments, but to ensure the court receives comprehensive and insightful submissions on the legal issues involved in an appeal. As well, the *amicus* program allows the court to ensure continuity of *amicus* counsel's involvement if a patient appears before the court on multiple occasions.

Justice Marc Rosenberg, who supervises the *amicus* program on behalf of the court, states that the submissions of *amicus* counsel provide invaluable assistance to the court. "These are important and often difficult cases and the expertise of *amicus* helps to ensure that the members of the court fully understand the complexities of these cases and the special vulnerabilities of these appellants."

"With the assistance of *amicus* counsel, we are confident that all the issues that should be raised are placed before the court. As a result, the court is much better positioned to properly deal with mental disorder cases," he writes.

The court has received very encouraging feedback from advocates who regularly appear as *amicus* counsel before the court. Anita Szigeti, an experienced counsel who specializes in mental health law, reports that she greatly enjoys her work as an *amicus* lawyer. "I have found assisting unrepresented mentally disordered accused in the Court of Appeal as *amicus* a truly rewarding experience," she writes.

"*Amicus* counsel play a unique role in these appeals. While we are there to support the position of the accused as much as possible to level the playing field, we are also there to assist the court, such that we may raise any issue reasonably arising on the record, whether the accused has sought to advance the issue or not. Accordingly, the exercise of preparing an *amicus* factum is a thoughtful and creative one," she adds.

Daniel Brodsky and Michael Davies also have extensive experience working in the field of mental health advocacy. Both lawyers have observed that patients are very satisfied with the system for appointing *amicus*.

"The impression that I get from the patients who have *amicus* appointed is that they like the fact that they get to present to the court themselves and also have a lawyer make some arguments for them," writes Mr. Davies.

"These are individuals whose opinions and views on matters are often ignored. I think some of the patients leave these appeals feeling that someone has actually listened to them for the first time."

Mr. Brodsky emphasizes that the benefits of the program extend beyond the courtroom. "The program offers an unforeseen benefit to all stakeholders in facilitating a non-adversarial forum to meet, brainstorm and put into practice methods of attenuating problems," he writes.

The *amicus* program is fortunate to have a group of committed, talented mental health lawyers who will help ensure the program's success in the future. Judges, court staff, prosecutors and patients all benefit from the continued efforts of *amicus* counsel to assist the court with the just resolution of Ontario Review Board appeals. The court is committed to continuing and improving this program, which greatly benefits some of the most disadvantaged litigants who appear before the court.

*Larissa Ruderman is counsel to the Court of Appeal of Ontario and co-ordinator of *Amicus Curiae* appointments.

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1 R.S.C., 1985, c. C-46.

THE BIG CASES THAT CHANGED THE LANDSCAPE

Anita Szigeti*

Since the Psychiatric Patient Advocate Office's (PPAO) inception now twenty-five years ago, much has changed for persons with serious mental health issues in Canada. All clients in Ontario now know that their right to refuse psychiatric medications is one that the *Charter of Rights and Freedoms*[1] protects. It is a right only subject to interference where the person loses capacity to make these decisions. Forensic psychiatric clients, those found unfit to stand trial (UST) or not criminally responsible (NCR) no longer languish in hospitals "at the pleasure of the Lieutenant Governor" as they once did. That this is the state of the law now is something easily taken for granted. However, it wasn't always inherently understood that individuals with serious mental health issues had any rights at all. It is largely through the good work of many advocacy organizations, dedicated consumer/survivor groups and a committed group of lawyers in this province that fundamental change has come about. The PPAO has been instrumental in bringing about many of the positive changes in the protection and advancement of the legal rights of our clients. A particularly impressive contribution was made by one-time legal counsel to the program, David Giuffrida, who spent nearly fifteen years at the PPAO, and in the process established the Mental Health Legal Committee, which has taken on a big part of the responsibility for taking these important cases forward. And of course, in the beginning there was ARCH, (now Superior Court Justice) Anne Molloy and Carla McKague, who together kick-started the litigation our current generation of lawyers is proud to continue. The landscape has truly changed for our clients in Ontario over the last twenty-five years. There is great room yet for improvement, which we hope to see over the next twenty-five years, but the anniversary of the PPAO is a lovely opportunity to reflect upon all that has been accomplished.

Most of the leading cases in this area of law do not, in fact, change the law. With the notable exception of *R. v. Swain*[2] in the Supreme Court of Canada, which gave rise to the Review Boards across the country that now monitor the situation of UST and NCR accused, the balance of the appellate consideration of legislation as it relates to our clients rights did not necessarily result in new laws. Rather these cases tend to set the record straight, so to speak, by clarifying the intent of existing legislative provisions, through a process known as statutory interpretation. Where there are a number of different ways a piece of law can be read, the Courts have assisted us over time in ensuring that they are read in line with the values and rights protected by our *Charter*, and hence ensured that the liberty interest of clients with serious mental health issues is protected as much as possible while safeguarding the public's safety and in some cases, that of the individual him or herself. In this short paper, I will look only at the legal rights of our clients to make their own treatment decisions and the situation of accused under the *Criminal Code*[3] Review Boards' jurisdiction (i.e., the UST or NCR accused under the Ontario Review Board in Ontario).

Treatment

In 1991, the Ontario Court of Appeal heard an appeal by a couple of patient inmates at Oak Ridge (Ontario's only maximum secure forensic psychiatric facility) who were unhappy that once declared incompetent, their prior capable wishes to refuse antipsychotic medications could be ignored by their doctor as long as the treatment was in their best interest, as the legislation at that point allowed. In addition to directing that this aspect of the legislation be brought in line with *Charter* values, Ontario's top court made the following seminal statement, that has now been quoted and cited in innumerable cases and articles and ultimately was adopted by the Supreme Court of Canada in *Starson v. Swayze* in 2003, some twelve years later. This is what Justice Robins said, on behalf of the unanimous panel, in 1991:

> The common law right to bodily integrity and personal autonomy is so entrenched in the traditions of our law as to be ranked as fundamental and deserving of the highest order of protection. This right forms an essential part of an individual's security of the person and must be included in the liberty interests protected by s. 7. Indeed, in my view, the common law right to determine what shall be done with one's own body and the constitutional right to security of the person, both of which are founded on the belief in the dignity and autonomy of each individual, can be treated as co-extensive.[4]

And the Court went on to comment that:

> Few medical procedures can be more intrusive than the forcible injection of powerful mind-altering drugs which are often accompanied by severe and sometimes irreversible adverse side effects. To deprive involuntary patients of any right to make competent decisions with respect to such treatment when they become incompetent, and force them to submit to such medication, against their competent wishes and

> without the consent of their legally appointed substitute decision-makers, clearly infringes their Charter right to security of the person.[5]

Next up, in 2003, the Supreme Court of Canada released its decision in *Starson v. Swayze*.[6] There was really nothing earth-shattering about this case, which turned entirely on its specific facts, apart from the confluence of the timing of the case with the release of the film version of the life of John Nash, the famed mathematician who suffered from schizophrenia, played by Russell Crowe in "A Beautiful Mind." As a result of the case catching the public's imagination, there were literally hundreds of newspaper articles in Canada and around the world which referenced the case and it received an enormous amount of every kind of media attention imaginable. The Court's decision (by a majority of 6 to 3) also divided lawyers, psychiatrists, consumer/survivors and the general public as to the wisdom of the outcome. In sum or substance, the Court elucidated the definition of "capacity" in the treatment decision-making context, and set a low threshold for finding an individual capable to make these decisions. Existing legislation in Ontario was not changed by the judgment. The Court simply interpreted capacity to include recognition of the possibility that one's mood or behaviour is affected by some condition, without requiring the subject of the assessment to agree that he or she suffers from a particular, or any, mental disorder, per se. As long as the individual was not in total denial of the possibility that there may be something wrong, basically, the person retained the right to refuse treatment. As long as the patient retained the capacity to understand information provided to him and the ability to appreciate the consequences of the decisions he made, he was entitled to weigh the value of the information differently than others would and make a decision many reasonable people would consider foolish. This infuriated many opponents of the decision. What most people tend not to appreciate, however, is that the *Charter* protects against unwanted interference with bodily integrity, and not any "right to treatment" which many physicians and families advance. It is not that their position is unsympathetic in many ways, but it is not the law.

Forensic Clients – The UST and NCR Accused

The Supreme Court of Canada has considered the situation of accused found not criminally responsible for their conduct in relation to criminal offences charged on at least six occasions in the last twenty-five years. In 1991, the federal government put in place the current Review Board system (Part XX.1 of the *Criminal Code*), where each province or territory has established an administrative tribunal which reviews the situation of accused under its jurisdiction at least annually. This system was created in response to the seminal case of *R. v. Swain*, wherein the constitutionality of the former not guilty by reason of insanity (NGRI) regime was successfully challenged. In summary, the Supreme Court ruled that we no longer get to literally lock up the mentally ill and throw away the key. Starting in 1999 then, the difficult task of interpreting what the new mental disorder provisions of the *Criminal Code* meant, began in earnest at the level of the Supreme Court of Canada. The Court first released its pivotal judgment in *R. v. Winko*,[7] defining what is meant by 'significant threat.' Up until that point, where Review Boards could not decide if an accused continued to pose a significant threat to the public's safety, they could continue jurisdiction over the accused. In *Winko*, a Charter challenge was brought to the indefinite nature of the detention, notwithstanding now annual reviews, and a plea was made to enact previously gray-shaded capping provisions (which would have limited detention under the mental disorder provisions to the maximum sentence for a particular index offence). The Supreme Court upheld the constitutionality of the new regime, provided the Review Boards only continued jurisdiction over the accused in the face of evidence based on which they could positively find that the accused continued to pose a significant risk of significant harm to the public's safety, in that the accused was likely to re-engage in criminal conduct without the Board's oversight. Otherwise, the Board had to discharge the accused absolutely. Since then, many accused who would otherwise still remain within the forensic psychiatric system have indeed been discharged for good.

In the years to follow, the Supreme Court of Canada held that the Review Boards are expert tribunals whose decisions on factual matters and issues of mixed fact and law are deserving of judicial deference and to be reviewed on a reasonableness standard (*R. v. Owen*),[8] whereas issues of statutory interpretation by these tribunals are reviewed on a correctness standard and are not entitled to deference. The Supreme Court also considered the question of conditions of detention or discharge in the context of forensic accused, and re-defined how the tribunal must make the least onerous and least restrictive disposition order in *R. v. Tulikorpi*[9] and *R. v. Pinet*.[10] The Court directed these boards to look at the entire package of the disposition order, including the conditions, to determine what constitutes the least restriction on the liberty of the accused, which the Court identified must be the predominant preoccupation of the tribunal, second only to protection of the public's safety. And finally, in *R v. Mazzei*,[11] the Supreme Court of Canada confirmed that Review Boards have the power to make orders which bind parties to their proceedings, other than the accused, and can therefore direct the hospital where an accused is detained to get an independent risk assessment done for the accused, re-formulate his treatment plan and, for instance, make efforts to enrol an aboriginal accused in culturally appropriate services, as the facts of that case warranted.

Overall, individuals with serious mental health issues have made great strides toward protection and advancement of their civil and legal rights in the last quarter century. The PPAO is commended for its role in achieving these goals for its clients. Congratulations PPAO!

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1 Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.
2 [1991] 1 S.C.R. 933.
3 R.S., 1985, c. C-46.
4 *Fleming v. Reid* (1991), 4 O.R. (3d) 74 (C.A.) at para. 39.
5 Ibid. at para. 40.
6 [2003] 1 S.C.R. 722. Indexed as *Fleming v. Starson* in the Supreme Court of Canada because Dr. Fleming was, at the relevant time of the final appeal, Starson's treating physician. And yes, it is the same Dr. Russ Fleming as in *Fleming v. Reid*.
7 [1999] 2 S.C.R. 625.
8 [2003] 1 S.C.R. 779.
9 [2004] 1 S.C.R. 498.
10 [2004] 1 S.C.R. 528.
11 [2006] 1 S.C.R. 326.

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LEGAL RIGHTS AND BENEFITS FOR CONSUMER/SURVIVORS

Lana Kerzner*†

Introduction

Consumer/survivors[1] often do not see themselves as people with disabilities.[2] At the same time, laws in Canada make the relationship between consumer/survivors and disability a current reality. The legal concept of disability in Canada today is broad and definitions of disability often specifically include mental disability. Some view this as a welcome development. Both consumer/survivors and people with other disabilities have a history of being subject to discrimination.[3] Laws are an important tool for addressing the unequal treatment and barriers they face. In fact, the progress of the consumer/survivor movement is impeded by laws which arbitrarily exclude them from definitions of disability.

Shifting the Dialogue from Stigma to Legal Rights

Stigma relating to consumer/survivors has endured for centuries.[4] The exclusion and marginalization that accompanies it requires the active enactment and enforcement of legal rights. Many consumer/survivors have been calling for a shift from the discourse of stigma (negative attitudes behind actions)[5] to that of human rights and discrimination (actions that exclude people).[6] Enforcing the right to equality will hopefully move consumer/survivors closer to achieving full inclusion.

The Legal Concept of Disability: Where do Consumer/Survivors Fit?

A broad multi-dimensional understanding of disability is the currently favoured approach.[7] This approach is often referred to as the social model of disability or the human rights model of disability. It has been accepted and articulated by recent Supreme Court of Canada jurisprudence and in the United Nations *Convention on the Rights of Persons with Disabilities* (*Convention*).[8] It describes disability as the outcome of the interaction of the person and their environment.[9] Accordingly, society's failure to accommodate the needs of people with disabilities, not an inherent mental or physical condition, gives rise to the 'disabling disadvantage' that they encounter in their daily lives. Health problems alone do not prevent people from participating in society. Rather, it is the obstacles in the socio-economic and built environment that do.[10]

The Supreme Court of Canada has accepted this "social model" of disability, as distinguished from a "medical model" in both *Québec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City)*; *Québec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*[11] and *Granovsky v. Canada (Minister of Employment and Immigration)*.[12] In *Granovsky*, the Supreme Court stated that there are three aspects to disability: physical or mental impairments; functional limitations, whether real or perceived; and the "problematic response of society to the [individual's] condition. A proper analysis necessitates unbundling the impairment from the reaction of society to the impairment, and a recognition that much discrimination is socially constructed."[13] The Supreme Court of Canada has stated that disability should not be confined within a narrow definition. Rather, the Court stated that it is more appropriate to leave room for flexibility and propose a series of guidelines that will facilitate interpretation. The *Convention*, too, adopts the social model.[14]

This model is not described in relation to a specific disability or type of disability. However, its relevance to and acceptance by the consumer/survivors movement has been questioned. Nonetheless, the practical effect of the direction of Canadian laws and the *Convention* is a broad understanding of disability which includes consumer/survivors in rights protections.

Specific Laws and Government Programs: Existing Legal Rights and Exclusions

Different pieces of legislation define disability in different ways depending on their purpose and intent. Laws that entrench equality rights and freedom from discrimination describe disability in very broad terms because the public policy intent is to prohibit, comprehensively, all forms of discrimination. "Mental disability" is usually specifically included. For example, the Canadian *Charter of Rights and Freedoms*[15] (*Charter*) refers to "mental disability" and "physical disability" in section 15. The *Canadian Human Rights Act*,[16] too, defines disability to include "mental or physical disability and includes disfigurement and previous or existing dependence on alcohol or a drug." As well, both the *Accessibility for Ontarians with Disabilities Act, 2005*,[17] and Ontario's *Human Rights Code*[18] contain a very detailed definition, including "a condition of mental impairment" and "a mental disorder."

Disability income program legislation and guidelines may define disability more narrowly, based on medical criteria, and/or may focus specifically on unemployability due to disability, and/or may look more broadly at a person's functional limitations in performing activities of daily living.[19] Even so, these definitions tend to be broad enough to include "mental disability." For example, the *Ontario Disability Support Program Act* defines a "person with a disability," as a person who has, *inter alia*, a "substantial physical or mental impairment."[20] The *Canada Pension Plan*, too, includes "mental or physical disability" in its definition of disability.[21]

The pattern found in Ontario and federal laws of including "mental disabilities" is in line with the *Convention*, which also casts a very wide net. While the *Convention* does not include a specific definition of disability, it states that "[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[22] It is noteworthy that the *Convention* deliberately excludes a specific definition of disability. It has been stated that the rationale for this choice was that any definition would necessarily exclude some people.[23] Including a definition was also seen as potentially undermining the *Convention's* commitment to the social model of disability.[24]

Even though many laws that apply to people with disabilities specifically define disability to include consumer/survivors, reform is still very much needed. Some disability-specific laws and government programs cover a wide variety of disabilities but exclude mental disabilities. There does not appear to be a rational or justifiable reason for doing so. For example, the Ontario government's Assistive Devices Program[25] provides funding for assistive devices. To be eligible for funding, an individual must have a physical disability and people with a "primary diagnosis of a learning or mental disability" are excluded from the program.[26] Similarly, the *Workplace Safety and Insurance Act*[27] entitles workers who sustain workplace injuries to benefits. However, a limitation is imposed on entitlement to benefits for people with mental health disabilities through exclusionary rules. These same rules do not apply to people with physical disabilities.[28]

Exclusion of consumer/survivors can also occur because of the manner in which laws and programs are administered. For example, while the definition of disability in the *Ontario Disability Support Program Act* includes "mental impairment," as a practical matter, the application process presents a barrier for many consumer/survivors.[29]

Ultimately, then, while there are several broad laws which include "mental disabilities" in their definition of disability with their concomitant granting of fundamental rights, other laws and programs specifically exclude them, in a seemingly arbitrary manner. Two important conclusions emerge. Firstly, many laws grant rights and benefits to consumer/survivors. Reliance on and enforcement of these laws may be an essential step to achieving inclusion and equality. Secondly, the consumer/survivor community should consider advocacy efforts to reform those laws that are exclusionary or that are interpreted or applied in an exclusionary manner.

The Next Step: Achieving Equality and Inclusion through Education and Rights Enforcement

The voices and experiences of consumer/survivors must inform the actions of all members of society. However, change will not occur by focusing exclusively on stigma. Society must be made aware of the discrimination that currently exists. They must be made aware of the right to equality and inclusion, and have an understanding of what this means for consumer/survivors.

It is equally important that consumer/survivors understand the legal rights to which they are entitled. Legal avenues available, such as making a human rights complaint or taking legal action on the basis of a violation of the equality provision (section 15) of the *Charter of Rights and Freedoms*, can be powerful tools for change. Because availing oneself of many of these remedies requires that an individual fit within a legal definition of disability, consumer/survivors would have to identify themselves as people with disabilities, and this may be problematic. Some have never considered themselves as people with disabilities so would not imagine that they can take advantage of legal rights for people with disabilities. Others make a conscious choice not to see themselves as disabled.

While not in any way a complete panacea for the long history of exclusion and discrimination experienced by consumer/survivors, education is a crucial next step. Armed with knowledge about their legal rights, consumer/survivors and their advocates can make informed decisions about whether to enforce their rights to equality and avail themselves for government programs and benefits.

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[†] I would like to express my sincere appreciation to Ruby Dhand, articling student at ARCH, for her research assistance. While the topic of this article is relevant throughout Canada, the article covers only federal and Ontario laws.

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1 This paper uses the term "consumer/survivor" to describe people with mental health problems. There are several other terms used to describe people with mental health problems and there has been long standing debate and no consensus on appropriate terminology. Other terms in use include: psychiatric survivors, psychiatric disability, mental disability and people with mental illness.

2 In fact, it has been stated that "[m]any psychiatric system survivors are unwilling to see themselves as disabled" cited in Peter Bersford, "What have madness and psychiatric system survivors have to do with disability and disability studies?" (2000) 15.1 Disability and Society 167 at 169.

3 *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624 at para 56; *R. v. Swain*, [1991] 1 S.C.R. 933 at para 39; Beresford, *ibid* at 169 and 170.

4 Neasa Martin and Valerie Johnston, "A Time For Action: Tackling Stigma and Discrimination," online: Mental Health Commission www.mentalhealthcommission.ca/documents/TimeforAction_Eng.pdf accessed 20 February 2008 at 9 [A Time for Action].

5 Stigma has been described as a "…social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group" cited in A Time for Action, supra note 5 at 8; Mental Health Commission, "Moving Forward Together: Stakeholder Perspectives on the Priorities of the Mental Health Commission of Canada," online: Mental Health Commission www.mentalhealthcommission.ca/documents/MHCC_StkhldrRprt.pdf accessed 20 February 2008 at 6 [Moving Forward Together].

6 Moving Forward Together, supra note 6 at 6; A Time for Action, supra note 5 at 11 and 21 -22; Lana Frado, "Speaking Of," *Sound Times Zine* 1:4 (October 2007) at 1.

7 Mont states that the "…[m]edical model has recently been replaced by the social model of disability, which conceptualizes disability as arising from the interaction of a person's functional status with the physical, cultural, and policy environments" cited in Daniel Mont, "Measuring Disability Prevalance," (March 2007) online: World Bank http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf at 2 – 3; Human Resources and Social Development Canada, "Advancing the Inclusion of People with Disabilities," online: Human Resources and Social Development Canada www.hrsdc.gc.ca/en/hip/odi/documents/advancingInclusion06/index.shtml at 74 [Advancing the Inclusion]; Arlene S. Kanter, "The Globalization of Disability Rights Law" (2003) 30 Syracuse J. In'l & Com. 241 at 247.

8 G.A. Res. 61/106, 76th plen. Mtg., U.N. Doc A/Res/61/106 Dec. 13, 2006 [hereinafter *Convention*].

9 Measuring Disability Prevalence, *supra* note 8 at 3.

10 Advancing Inclusion, *supra* note 8 at 6.

11 [2000] 1 S.C.R. 665, 2000 SCC 27 [*Mercier*].

12 [2000] 1 S.C.R. 703, 2000 SCC 28 [*Granovsky*].

13 *Granovsky, ibid* at paras. 29-30.

14 Kanter, *supra* note 8 at 291-292.

15 Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

16 R.S.C. 1985, c. H-6, s. 25.

17 S.O. 2005, c. 11, s. 2 [AODA].

18 R.S.O. 1990, c. H.19, s.10(1).

19 ARCH Disability Law Centre, "Providing Legal Services to Persons with Disabilities," Bar Admission Course 2006-2007 (Toronto : Law Society of Upper Canada, 2007) online: ARCH Disability Law Centre www.archdisabilitylaw.ca/publications/archPapers.asp accessed 15 April 2008 at 8.

20 S.O. 1997, c. 25, Sched. B, s. 4 [*ODSPA*]. The definition of disability for income support looks at a person's limitations in performing activities of daily living, as well as medical criteria. While this definition does include mental impairment, the Ontario Disability Support Program is seen to contain substantial barriers for consumer/survivors to access the program. See discussion above.

21 R.S.C. 1985, c. C-8, s.42(2). The definition of disability in s.42(2) is based on medical criteria, duration, as well as unemployability.

22 *Convention*, Article 1, *supra* note 9.

23 Kanter, *supra* note 8 at 292.

24 Kanter, *supra* note 8 at 292.

25 The Assistive Devices Program is a program of Ontario's Ministry of Health and Long-Term Care. Information about this program can be accessed at Ministry of Health and Long-Term Care, "ADP: All About the Program," online: Ministry of Health and Long Term Care www.health.gov.on.ca/english/public/pub/adp/about.html accessed on 29 February 2008.

26 *Ibid.* and Ministry of Health and Long-Term Care, "Policies and Procedures Manual for the Assistive Devices Program (ADP)," (Ontario: Ministry of Health and Long-Term Care, 2006), Section 6, 600.02 at 60.

27 S.O. 1997, CHAPTER 16, Schedule A.

28 *Ibid.*, s.13(4) and (5); Workers Safety and Insurance Board, "Traumatic Stress," online: Workers Compensation and Insurance Board www.wsib.on.ca/wsib/wopm.nsf/Public/150302 accessed 20 February 2008.

29 Street Health, "Failing the Homeless: Barriers in the Ontario Disability Support Program for Homeless People with Disabilities," online: Street Health www.streethealth.ca/Downloads/FailSum.pdf 1 and 3 – 4. This was a study of homeless people living with disabilities in Toronto, Ontario, 38% of whom "…had been diagnosed with severe mental health conditions" and 82% of whom "…suffered from other serious mental health conditions" at 2.

THE MENTAL HEALTH CLIENT'S RIGHT TO COUNSEL

Julian Kusek*

What is a right if it can't be asserted? What is justice if it can't be accessed? Who will speak for you when you are not able? All these questions have special meaning for vulnerable populations. Few have such a concentration of vulnerability factors as do mental health clients – poverty, dual-diagnosis, illiteracy, medical issues, no family support, societal stigma, racial discrimination – the list can go on. Admirably, there are many programs and initiatives to support clients in legal need; however, it all boils down to a one-to-one relationship between a client and their counsel. That relationship and the legal advocate's dedicated pursuit of their client's best interests can turn a client's fortunes around. While there can be no guarantee of a solution in the client's favour, the lawyer's work can generate change in the person's life and can assist in the client's journey towards recovery.

The Psychiatric Patient Advocate Office (PPAO) works to support clients who seek or are in need of legal representation. We have the ability granted by Legal Aid Ontario to complete legal aid applications for clients situated at Ontario's ten mental health centres. We assist clients to find counsel of their choice who are funded by Legal Aid Ontario.

At times, we find ourselves in a corridor with the client's cell door "cracked" so that you can slide the legal aid application to the client who is only permitted to sign with a crayon due to risk considerations. For that client, the situation is indeed rock bottom. The road out, the road to recovery, begins with the application and the chain of events which follow.

As such, the PPAO is a portal to access justice for a portion of the mental health population. Access for mental health clients translates into a right to counsel. There are statistics compiled by the Ontario Ministry of the Attorney General which show that the average percentage of unrepresented litigants in Ontario family courts between 1998 and 2003 was 46%. This is a startling number; nonetheless, lay persons still have some ability to conduct a defence or advance their case with some preparation or assistance. The mental health client has disabilities which in many cases do not impact their ability to live a good life; however, they do severely impact their access to justice. I am cautious of the negative use of the "dis" in "disabilities" because it unfairly and unjustly focuses on what a client may not be able to do readily and further fails to promote or celebrate what clients are perfectly able to do. A client may be illiterate, but that client may still be able to plead their case in open court and recall from memory every injustice done to them by "the system." The lay drafting of a factum on contested points in fact and/or law may be poorly done by legal standards but it can tell the client's story. The story would be compelling and all the more because the client is telling it in his or her own words. It is not the fault of the person accessing the system that he or she can't follow the framework for recourse, but the failure of the process to adapt their procedures and attitudes to facilitate the positives.

There is hardly a situation where administrative boards or courts don't exercise patience and understanding of a litigant with mental health issues, but not all have an ability to really listen to the client and allow the client to plead their own way. Lawyers in a support role often need to stay in the background and assist when an opportunity presents itself.

Clients often talk of "the system" as it is there wherever they turn and can present more obstacles than they can circumvent. They know the truth – there is indeed a system, and moreover, that system is powerful. Resources are relatively limited on the client's side but well-resourced on the other side - government lawyers, psychiatrists, clinical staff, police, policies and procedures, administrative support and the list goes on. From the client's perspective, the odds are certainly against them though the system will contend that it exists for the client's welfare. Facing such odds, every client knows that a "good lawyer" is essential to redress the power imbalance.

Many believe that clients may not be able to make a "correct" decision or provide an instruction in their best interest. There are three types of patient advocacy – instructed, non-instructed and self-advocacy. The PPAO's prime directive is to follow client instructions; failing such instructions, we act in the client's best interest, but only if no instruction from a client is forthcoming. What I learned early on as a patient advocate is that most clients know what they want and can give instructions. Instructed advocacy is best as you can work with clients and align your advocacy with their specific wishes. We are not gatekeepers. Gatekeeping is a regulatory function premised on acting only if you think it is wise and sensible as opposed to the client who may have a different view. This is directly contrary to a patient advocate's role which is ultimately to empower and assist the client in his/her journey to recovery. The PPAO functions at this level and can complement the role of lawyers in their work.

Lawyers, like any other profession, vary in competence and ability to empathize with clients. There is a core of lawyers who practice mental health law on a regular basis. Their real strength is that they actually care about their client's welfare. It takes the lawyer's fiduciary role to a higher level. They know that their clients are at the end of the line and hanging on for dear life. In fact, legal aid pays relatively poorly and many lawyers have other areas of practice to supplement their income. It is also not the thrill of victory that attracts good lawyers for in many instances the cases are not won for a variety of reasons.

Once the legal application is reviewed and accepted, counsel who have accepted the mandate to represent the client will receive a certificate for the case and can commence their work and billing to Legal Aid Ontario. The great majority of certificates relate to applications to the Consent and Capacity Board, the Ontario Review Board and the courts dealing with criminal offences. Our role is at the commencement and to assist in setting up the lawyer-client relationship. I would like to highlight situations which will provide insight to difficulties early on in the process.

Refusal: Client not in jeopardy of jail sentence

Clients who face criminal charges often have recourse to the court diversion program. For certain charges, the Crown attorney will divert the matter from the criminal court and cause a stay of proceedings or withdrawal of the charge(s). Many times, the client is not initially represented by their own counsel. They may be fearful and not ask for their own counsel and seek legal aid funding. If the person does not apply, the person at Legal Aid Ontario reviewing the application may come to the conclusion that the charge would not result in incarceration (loss of liberty) and the application is refused. But, there is always the chance of incarceration and clients fear jail. Only their own counsel can fully speak for them, as opposed to duty counsel or court staff.

Refusal: No merit for appeal

A central right for any patient is the right to refuse treatment. It is not an absolute right, as the client must have the requisite capacity to consent or not consent to psychiatric treatment. A physician cannot seek consent to treatment from a client the doctor believes is an incapable client even though the client wants and agrees to the treatment. The ethical course of conduct is to make the client incapable and then seek the consent of a substitute decision-maker. The client can object and take the issue to the Consent and Capacity Board and Legal Aid Ontario normally grants certificates for the hearing. The hearing can be quite intense as the client is not only hanging onto their self-image but also a rational fear of the drug and its side-effects. If treatment has not commenced, then it cannot start until a decision is rendered by the Consent and Capacity Board. If a client loses at the hearing stage, then an appeal to the Superior Court will suspend treatment. Once the appeal process has expired and the client is not successful, then the client can be provided the treatment – even under force.

Legal Aid Ontario issues certificates for the initial hearing without questioning the merits. At the appeal stage, it requests a favourable legal opinion from counsel before funding an appeal. This doesn't always happen and only rarely if the client was self-represented at the hearing. Further, there are only a small group of lawyers who will appeal decisions and they all require funding which may not be forthcoming. Without an appeal, there are many lost opportunities for jurisprudence which would have advanced the law.

The issue is not if the outcome of a case was the proper one, although the client would undoubtedly disagree. For us, it is whether due process has been followed. It is very evident that without a lawyer, a number of cases would fail and the client would have been subjected to forced treatment.

Conclusion

Legal aid funding has many checks and balances that impact the availability of legal representation for mental health clients. A fresh review of the process is required so that more lawyers are brought into the process. More lawyers are needed who can empathize and assist in providing hope on the client's journey towards recovery. The true bellwether of whether we are still a caring and just society is how well we defend the rights of vulnerable populations.

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PHIPA - ENFORCING OR ERODING RIGHTS FOR PSYCHIATRIC PATIENTS?

D'Arcy J. Hiltz*

Without an effective remedy to review denials of access to personal health information or to review findings of incapacity regarding disclosure, collection and use of personal health information (for individuals assessed not capable of treatment and who have a substitute decision maker), the *Personal Health Information Protection Act*[1] (hereinafter referred to as *PHIPA* or the *Act*) has not only eroded but rendered the rights of psychiatric patients meaningless.

Purposes of PHIPA

The stated purposes of *PHIPA* are to:

a) Establish rules for the collection, use and disclosure of personal health information about individuals that protect the confidentiality of that information and the privacy of individuals with respect to that information, while facilitating the effective provision of health care;

b) Provide individuals with a right of access to personal health information about themselves, subject to limited and specific exceptions set out in this *Act*;

c) Provide individuals with a right to require the correction or amendment of personal health information about themselves, subject to limited and specific exceptions set out in this *Act*;

d) Provide for independent review and resolution of complaints with respect to personal health information; and

e) Provide effective remedies for contraventions of this *Act*.[2]

Access versus Collection, Use and Disclosure of Personal Health Information

PHIPA makes a significant distinction between obtaining access to personal health information and consenting to the disclosure, use and collection of personal health information.

Access

An individual may be denied the right of access to their personal health information based on any number of criteria including the following:

1. If access could reasonably be expected to result in a risk of serious harm to the treatment or recovery of the individual;
2. If granting the access could reasonably be expected to result in a risk of serious bodily harm to the individual or another person;
3. If granting the access could reasonably be expected to lead to the identification of a person who was required by law to provide the information in the record to the custodian; or
4. If granting the access could reasonably be expected to lead to the identification of a person who provided information in the record to the custodian explicitly or implicitly in confidence if the custodian considers it appropriate in the circumstances that the name of the person be kept confidential.[3]

Disclosure, Collection and Use

An individual may be denied the right to consent to the disclosure, use of collection of their personal health information based on a finding that they are not capable.[4]

Based on this distinction, capacity or lack thereof is relevant only in relation to collection, use and disclosure but not access. This is of significance when there is a denial of personal health information. For example, "access" to personal health information appears to be confined to the situation where an individual makes a request to obtain their own personal health information.[5] "Disclosure," "collection" or "use" appears to relate to those situations where someone other than the subject of the information (referred to in the *Act* as a health information custodian) seeks to provide disclosure of the health information to someone other than the subject of the information; or seeks to collect personal health information about the subject from someone other than the subject; or seeks to use the personal health information of the subject.[6]

However, the question to be answered is: "what criteria are applied and what remedies are available where an individual requests a health information custodian to provide personal health information about themselves to a third party?" Is this a request for "disclosure" (where capacity is required), or is this a request for "access" (where capacity is not a ground of denial)? This lack of clarity has resulted in uncertainty as to what test to apply in relation to a denial and more significantly, what remedy if any, is available based on how the request is classified.

Rights Regarding a Denial of Access Prior to PHIPA

Prior to *PHIPA*, if a psychiatric patient requested access to their personal health information and the officer in charge of the psychiatric facility was of the opinion that access would result in either serious harm to the treatment or recovery of the patient while in treatment at the psychiatric facility, or serious physical harm or serious emotional harm to another person, there were statutory obligations and efficient timelines imposed by the *Mental Health Act* on the person seeking to withhold the information if access was to be denied to the patient.[7]

Firstly, the onus was on the officer in charge to apply to the Consent and Capacity Board for permission to withhold the personal health information from the patient. The officer in charge was also required to provide the patient with written notice of the application and the grounds for denying access.

Secondly, the application of the officer in charge had to be submitted to the Consent and Capacity Board within seven days from the date the patient made the request for access.

Thirdly, the Consent and Capacity Board was required within seven days from receipt of the application to review the personal health information and direct the officer in charge to allow the patient access unless the Board was satisfied that the criteria for refusing access was met.

Rights Regarding a Denial of Access under PHIPA

Under *PHIPA*, the statutory obligations and efficient seven day timelines of the *Mental Health Act* were eroded. In fact, under *PHIPA* there is no longer an independent review of the personal health information by the Consent and Capacity Board and no longer an obligation on the person seeking to withhold the information to establish grounds for refusal. Instead, what one is left with under *PHIPA* is a cumbersome and confusing procedure requiring the psychiatric patient or other person seeking access, to determine who to apply to and the grounds for the denial of access. For example, under *PHIPA*, the person who receives the request for access now has up to sixty days from the date the request is made to respond indicating either that: (1) they are refusing to confirm or deny the existence of any record and the person may complain to the Information and Privacy Commissioner under *PHIPA*; or (2) they are refusing to provide access based on one of the grounds specified and the person may complain to the Commissioner under *PHIPA*.[8]

The psychiatric patient or other person must then make a second and separate Application to the Commissioner under *PHIPA*, complaining about the response or lack of response received in relation to their first Application. Upon receipt of the second application, the Commissioner may then choose a number of courses of action to take, including a review. If the review is held, the Commissioner may make an Order either directing or refusing the access.[9]

Considering the rights previously granted to psychiatric patients under the provisions of the *Mental Health Act*, to conclude that the process of review under *PHIPA* has enhanced the rights of psychiatric patients, would not only be misleading but false.

Rights regarding a denial of Disclosure, Use, or Collection prior to PHIPA

Prior to *PHIPA*, psychiatric patients were either capable or not capable of examining or disclosing their personal health information. The *Mental Health Act* referred to, but did not distinguish between "examination", "disclosure" and "transmittal" of personal health information. It contained no reference to "collection" or "use." If a patient was assessed not capable to examine or disclose their personal health information record, they had the statutory right to have the finding reviewed by the Consent and Capacity Board.[10]

It is of significance that this right to review existed notwithstanding that the patient may have been assessed not capable of making treatment decisions with a substitute decision maker in place. In other words, capacity was seen as task specific. A patient not capable of making a treatment decision maintained the presumption of capacity to make a decision regarding the examination or disclosure of their personal health information.

This view of capacity as being task specific was later endorsed not only by the *Health Care Consent Act* but also the *Substitute Decisions Act*. For example, the *Health Care Consent Act* acknowledges that a person may be incapable with respect to some treatments and capable with respect to others.[11]

The *Substitute Decisions Act* acknowledges that a person may retain the capacity to make a power of attorney for property even though they are not capable of managing property.[12] It also acknowledges that a person may retain the capacity to make a power of attorney for personal care even though the person may not be capable of making a personal care decision including a decision regarding their health care.[13]

Rights regarding a denial of Disclosure, Collection, or Use under PHIPA

Does *PHIPA* acknowledge that capacity is task specific? The answer is unclear.

On the one hand, *PHIPA* acknowledges that an individual is presumed capable of consenting to the collection, use or disclosure of personal health information without any proviso that the presumption does not apply to a person found incapable of consenting to treatment with a substitute decision maker in place. In fact, *PHIPA* goes on at great length to address the issue of capacity being task specific. It states that an individual may be capable of consenting to the collection, use or disclosure of some parts of personal health information but incapable with respect to other parts. *PHIPA* also states that an individual might be capable of consenting to the collection, use or disclosure of personal health information at one time, but incapable of consenting at another time.[14]

On the other hand, *PHIPA*, after specifically confirming the presumption of capacity, proceeds to abolish the right to review a finding of incapacity for anyone not capable of consenting to treatment with a substitute decision maker. In other words, for individuals not capable of treatment who have a substitute decision maker (the majority of which are psychiatric patients), the right which previously existed under the *Mental Health Act* to review a finding of incapacity no longer exists. For this person, there is no remedy, there is no review. By taking away this remedy and this review, *PHIPA* has not only eroded but rendered the rights which previously existed for psychiatric patients, meaningless. A right to consent to the collections, disclosure and use of personal health information in the absence of a review and an enforceable remedy is a right which, when denied, is not only eroded, but meaningless.

Conclusion

Was this necessary? Were the benefits of allowing a review of incapacity regarding disclosure, use or collection of personal health information for a person not capable of treatment with a substitute decision maker in place, outweighed by the detriments? If so, what were the detriments? If the concern was that a person not capable of treatment with a substitute decision maker in place could prevent disclosure of information necessary for the substitute decision maker to make treatment decisions, the concern could have been easily addressed by the legislation allowing the substitute decision maker to obtain the information notwithstanding the capacity of the person to disclose, collect or use their personal health information.

In fact, the *Health Care Consent Act* allows a substitute decision maker to receive all information necessary to make an informed decision regarding treatment.[15] More importantly however is that if *PHIPA* acknowledges a presumption of capacity to consent to the disclosure, use and collection of personal health information, how can the same legislation justify removing a fundamental right to review a finding of incapacity regarding use, disclosure or collection for individuals not capable of making treatment decisions with a substitute decision maker? If there is any circumstance which warrants an enhancement of the right to review a finding of incapacity regarding disclosure, use or collection of information, it is the situation where an individual has lost the ability to make their own decisions regarding treatment. This is the most vulnerable of individuals. By taking away this review and this remedy, not only has there been an erosion of the right to examination and disclosure but a subtle and dangerous step backward in viewing capacity as non task specific. Under *PHIPA*, a person not capable of treatment is for all practical purposes, now presumed incapable of consenting to the disclosure, use or collection of personal health information.

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1 S.O. 2004, c. 3, Sch. A. [*PHIPA*].
2 *PHIPA*, s.1.
3 *PHIPA*, s.52(1)(e).
4 *PHIPA*, s.22.
5 *PHIPA*, s.53.
6 *PHIPA*, s.18.
7 *Mental Health Act*, R.S.O, 1990, c. M.7, s. 35 and s.36 prior to amendments resulting from *PHIPA*.
8 *PHIPA*, s.54.
9 *PHIPA*, s.56.
10 *Mental Health Act*, s.36(14) prior to amendments of *PHIPA*.
11 *Health Care Consent Act, 1996*, S.O. 1996, c. 2, Sched. A, s.15(1).
12 *Substitute Decisions Act, 1992*, S.O. 1992, c. 30, s.9(1).
13 *Substitute Decisions Act*, s.47(2).
14 *PHIPA*, s.21(2)(3).
15 *Health Care Consent Act*, s.22(1) and (2).

PHIPA - PRIVACY IN THE MENTAL HEALTH CONTEXT

Mary Jane Dykeman* and Kate Dewhirst**

The *Personal Health Information Protection Act, 2004* ("*PHIPA*")[1] came into force in November 2004. As legal counsel to hospitals and community mental health agencies in Ontario, we have seen the impact this legislation has had from the institutional, care provider, client and family perspectives.

Privacy issues have been top of mind for our mental health facility clients in the last four years. For all intents and purposes, the mental health sector was ahead of the game in comparison with other players in the broader health care system, given the fact that psychiatric facilities and their clients were used to a regime under the *Mental Health Act*[2] for access requests from clients and restrictions on disclosures. Still, when *PHIPA* first came into effect, mental health facilities, hospitals, and community organizations struggled with compliance.

The privacy landscape is much more sophisticated (and in many cases more complicated) now than it was prior to 2004. There have been significant investments of time and resources to reinforce a privacy culture across the health care sector. One of the most significant shifts we have witnessed in the last four years is the paradigm shift for care providers from dealing with "confidentiality rules" to respecting "privacy rights." In past, the rules focused on a care provider's responsibility to protect information from unauthorized disclosures (i.e., to individuals and organizations outside a specific mental health facility). While there were a number of new security and confidentiality standards introduced with *PHIPA*, the focus today is on the client and the client's ability to exercise choices about if and how health information will be collected, used and disclosed.

At the same time, the number of permitted collections, uses and disclosures of personal health information without client consent under *PHIPA* is notable. While in some instances these permit the flow of information to support a continuum of care, some of the limitations on the requirement to seek consent continue to be a cause for concern by clients and client advocates. With the advent of electronic systems in hospitals and community agencies and the increased focus on research into mental health and addiction issues, there are ever-increasing pressures to make personal health information more easily available and shared among providers and for a wider range of authorized collections, uses and disclosures.

Hot Topics in Mental Health Privacy

Variations in Privacy Practices

One of the primary objectives for the introduction of *PHIPA* was to establish common privacy rules and expectations across the health care system. Many pieces of health sector legislation (including Ontario's *Mental Health Act*) received complementary amendments to bring the existing disclosure, access to health records and confidentiality provisions in line. Now, regardless of where an individual receives health care, clients can expect the same level of privacy protection and choice about how information is exchanged. Unfortunately, there are still a wide range of practices among health care providers as to how these protections, rights and choices are implemented. So, there is still variety in practice for the following issues:

- the fees that are charged for accessing information;
- the forms that are used to document the choices made by clients;
- the degree to which particular mental health facilities and community agencies will exercise their discretion to collect, use and disclose personal health information based on implied consent, express consent or without consent; and
- variability in customer service in answering questions and responding to privacy complaints.

As time passes, we may see these service gaps narrow as facilities and health care providers become more accustomed to the law.

Sharing information within the circle of care

The concept of a "circle of care" within which health care providers may exchange personal health information relying on implied consent has had limited application in the mental health sector. Many of the community allies with whom psychiatric facilities work (e.g., housing, income maintenance, and supportive employment agencies) are not considered "health information custodians" under *PHIPA* and therefore sharing information with such agencies may only be done with express consent. This has not meant a change in practice – but we are still working out the parameters of who is in and out of an individual's circle of care. The concept of sharing information relying on implied consent (not having to have signed consent forms) has been confusing for clients and providers alike.

Disclosing information to the police

Some hospitals are working collaboratively with police departments to determine the circumstances under which the hospitals will release personal health information to the police without a warrant or court order for production. Most mental health facilities struggle with creating such protocols as there continues to be much sensitivity around the issue of release of mental health information to police. In practical terms, there is relatively little personal health information that must be shared immediately with police without receipt of a warrant or court order or consent for disclosure from the individual. However, it is extremely difficult for front-line staff to assess what should or should not be disclosed to the police (especially in an emergency). We have found that it is best for front-line staff to redirect any police request for information to the facility's risk management office, privacy office, or to a senior manager or lawyer. Some mental health agencies have found that developing a liaison committee with the local police division works well to iron out processes in advance of an actual crisis or risk situation. This is especially helpful given that many urgent police requests for information seem to unfold late at night or on weekends, where fewer resources are available to front-line staff.

Balancing privacy rights with a family-centred approach to care

Surveys of family members of mental health clients have identified "privacy" as one of the key areas of concern and sources of questions for families. In the first months (and years) of the implementation of *PHIPA*, family members were routinely met with a response of "I can't talk to you because of the new privacy legislation" when they made inquiries of health care providers about their loved ones or tried to offer information about a family member's status or behaviour. The privacy legislation has certainly increased awareness for care providers to engage their clients in determining the ways they wish to have their family members involved in their care decisions. Providers are now more nuanced in their responses to family members where clients have chosen not to share information by offering supports and general information to the families.

It should be noted that *PHIPA* permits certain confirmation information to be shared with families (and others) by certain facilities where an individual is receiving care (such as hospitals and long-term care facilities but not community mental health facilities). This information is limited to confirmation that the individual is present in the facility, location and general status (think of this as visitor or "florist" information – you can call up a hospital and ask where a family member is receiving care in the hospital in order to visit or send flowers). Such information can be released unless the individual has specifically asked that the information not be released. This provision in *PHIPA* has been a concern to some clients, to the extent that it could change the long-standing practice of mental health facilities of not giving out such information. Further, location in a mental health facility has the potential to identify the general nature of a client's illness (e.g., schizophrenia program). From a practical perspective though, many (if not most), mental health facilities have opted not to rely on this permissive provision in *PHIPA*, and continue to neither confirm nor deny whether an individual is a client of the facility. This is sometimes to the chagrin of worried family members, but it preserves the historic practice.

Lockbox

PHIPA provides clients an opportunity to provide express instructions to a care provider to shield certain information from other care providers, sometimes informally called a "lockbox." For example, a client could request that a mental health facility not share a diagnosis with a family physician, or community mental health agency. Similarly, a request could be made to ensure that a client's neighbour working in the facility not be privy to the client's health information. Despite the early worries about the lockbox creating roadblocks in the system and impeding care, most health care providers have continued to do what they had done previously: that is, they continue to work with clients to explore the source of their concerns and restrict access to charts and disclosure to information on the client's express consent. In some instances, a request for lockbox becomes a request for correction of the record, and vice versa.

What is most important is that health care providers and clients understand the limitations of the lockbox. A lockbox extends only to the flow of information between health care providers, and cannot be used to block collections, uses and disclosures of health information that are permitted or required by law (i.e., a lockbox cannot be used to: block internal use by the facility for teaching or risk management purposes; prevent disclosures to reduce or eliminate significant risk of serious bodily harm; or prevent mandatory disclosures under certain statutes such as the *Highway Traffic Act*[3]). Further, there continues to be authority under subsection 35(2) of the *Mental Health Act* that permits the collection, use and disclosure of personal health information without consent, where an individual is a client in a mental health facility pursuant to the *Mental Health Act* or under the mental disorder provisions of the *Criminal Code*.[4] In a few instances, the opportunity to shield certain information has led to unrealistic expectations for clients who thought the information "in a lockbox" would never be shared with anyone under any circumstances.

Access and Correction

Clients in the mental health system continue to have rights of access to, and correction of, their personal health information. However, the timeframes within which a health care provider has to respond to the access request have changed from seven days under the *Mental Health Act* to thirty days under *PHIPA*. As well, while the right of access permits the health care custodian under *PHIPA* to consult with a physician or psychologist where denial of access is proposed on the basis of harm, the automatic hearing before the Consent and Capacity Board has been lost. Now, if a client is denied access to his/her record of personal health information, the client has a right to make a complaint to the Information and Privacy Commissioner of Ontario.

The correction provisions under *PHIPA* are also of interest to those in the mental health community. Clients may ask for corrections to any incorrect information held in their records. While clients have a right to make correction requests, health care providers are not obliged to make changes to their professional opinions made in good faith (or to information from another provider if the health care provider lacks the information, knowledge and expertise to make the change). Where clients and health care providers disagree about a correction request, the client must be offered an opportunity to write a statement of disagreement, which is then attached to the record. However, this is not always a popular solution for clients who disagree with their diagnoses or information in their clinical reports.

Conclusion

PHIPA compliance efforts have offered an excellent opportunity for mental health facilities and health care providers to review a wide range of information management practices and engagements with clients. We are still in the early years of the legislated privacy regime and there are still some areas of privacy and health information management that raise concern for mental health and addiction sector clients and their families. However, from our experience, mental health facilities and health care providers are committed to establishing a coordinated health care system that optimizes client privacy rights and they will continue to work with clients, families, advocacy groups and the Information and Privacy Commissioner of Ontario to achieve that vision.

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The authors congratulate the Psychiatric Patient Advocacy Office on its 25th Anniversary and thank the PPAO for the opportunity to contribute to this compilation from across the mental health and broader health sectors.

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1 S.O. 2004, c. 3, Sch. A.
2 R.S.O. 1990, c. M.7.
3 R.S.O. 1990, c. H.8.
4 R.S.C, 1985, c. C-46.

A RESOLUTE AND HONOURABLE COLLECTIVE: THE MENTAL HEALTH LEGAL COMMITTEE

Marshall Swadron[*]

The Mental Health Legal Committee (MHLC) was formed in 1997 by a group of like-minded lawyers and community legal workers practicing mental health law. A wholly voluntary organization, the MHLC requires nothing from its approximately 100 members beyond a pledge to advocate for the legal rights of persons with mental disorder. Led for most of its existence by founding chair Anita Szigeti, the MHLC has accomplished much in its first eleven years.

The MHLC serves three main roles. The first is to raise the standard of advocacy of the mental health bar. This is achieved by providing access to peer support, mentorship and collective problem-solving by leading practitioners. MHLC representatives have participated in initiatives such as the establishment by Legal Aid Ontario of Consent and Capacity Board lawyer panel standards. The second role is to seek to influence changes in law and policy that impact clients with mental disorder. This has included submissions respecting the *Personal Health Information and Privacy Act, An Act to Amend the Law Society Act, Mental Health Reform 2000* (also known as "Brian's Law"), the *Public Hospitals Amendment Act* and the rules of practice of the Consent and Capacity Board, among others. The Committee has also successfully advocated for the removal of court filing fees in appeals from the Consent and Capacity Board. The third role, and the focus of this article, is the MHLC's interventions in leading court and tribunal cases affecting its constituency.

To date, the MHLC has been granted intervenor status at the Supreme Court of Canada on four significant cases affecting the rights of persons with mental disorder, specifically *Starson v. Swayze*,[1] *Odhavji Estate v. Woodhouse*,[2] *Pinet v. St. Thomas Psychiatric Hospital*[3] and *Penetanguishene Mental Health Centre v. Ontario*.[4] It has also intervened in the Human Rights Tribunal case of *Braithwaite v. Chief Coroner*,[5] appeals from which are presently before the courts. Each is considered in turn.

Starson v. Swayze

Starson v. Swayze was the first of four successful Supreme Court interventions by the MHLC. It also represents the first and only time, since the Review Board was created by the *Mental Health Act* of 1967, that Canada's highest court has granted leave to appeal from a Consent and Capacity Board decision.

Scott Starson had come into contact with the criminal justice system as a result of various non-violent incursions due to his bipolar disorder. While detained in hospital, the brilliant, self-taught physicist refused to consent to treatment with antipsychotic medications, describing prior medication attempts as "the most horrible experiences of my life."

As it does in most such applications, the Board upheld the attending physician's finding of incapacity, forcing Starson to bring an initial appeal to the Ontario Superior Court of Justice. Justice Anne Molloy found that the Board had misapplied the test for capacity, placing excessive emphasis on what it considered to be in Starson's best interests. She also expressed concern respecting the weight given by the Board to uncorroborated hearsay evidence. Based on the record, she concluded that Starson met the test for capacity and reversed the Board's decision. An unsuccessful appeal to the Court of Appeal by the physician set the stage for consideration by the highest court.

In a joint Supreme Court intervention with psychiatric survivor group the Mental Health Legal Advocacy Coalition (MHLAC), the MHLC placed emphasis on the avoidance of antipsychotic medications as a rational choice. The Board's requirement that Starson perceive his condition in negative terms (i.e., as an illness) in order to fulfill the requirements of capacity not only disregarded evidence of his comprehension but served to further the stigma surrounding mental disorder. It was argued that Starson had tried the treatment in question and was free to decide, based on his own experience, that the cure was worse than the disease.

The appeal was dismissed by a 6 to 3 majority led by Justice Major, with the Chief Justice writing for the dissenting judges. Applying the same test to the same facts, the majority and minority opinions were ultimately divided on the factual question of whether incapacity was demonstrated upon the evidence before the Board. In the main, the arguments of the MHLC found acceptance in the majority decision. The intervenors were unsuccessful on one issue, however. While the MHLC had argued in support of an enhanced standard of proof in treatment capacity matters, the Court stated the test as being on the civil standard of the balance of probabilities. Nevertheless, the decision was a clear victory for bodily integrity, cognitive integrity and personal autonomy.

Odhavji Estate v. Woodhouse

On the surface, the case of *Odhavji Estate v. Woodhouse* would seem to have little to do with the rights of persons with mental disorder. The underlying facts involved a lawsuit brought by the family of the late Manish Odhavji, an unarmed young man without any history of mental disorder shot by police as he attempted to flee from his car following a bank robbery. The police officers at the scene failed to cooperate with the civilian Special Investigations Unit (SIU), established to investigate injuries caused by the police, which nonetheless cleared the officers of wrongdoing. In the lawsuit, the family members alleged that the failure to cooperate with the SIU constituted misfeasance of public office and sought damages for the resulting mental distress, anger, depression and anxiety.

The defendants brought motions to strike out the claim on legal and public policy grounds and had succeeded in persuading a majority of the Ontario Court of Appeal that the tort of misfeasance of public office was not available to the plaintiffs. In the Supreme Court, the police and a number of governments lined up to support the Court of Appeal's ruling. Balancing the police interests were several intervenors, including the MHLC, seeking to expand the accountability of the police. The MHLC's involvement was a product of the frequent interaction of persons with mental disorder and the police, sometimes with tragic consequences. The MHLC's counsel, Suzan Fraser, had acted for the Queen Street Patients Council in the inquest into the death of Edmund Yu, who was shot by police in February 1997 (not coincidentally the month the MHLC was formed) while holding a hammer in the back of an evacuated Toronto Transit Commission bus.

The MHLC asserted that state intervention was relatively common for psychiatric survivors whose rights and liberties could only be maintained through the upholding of legal duties. Restrictively interpreting misfeasance of public office to exclude the deliberate failure of a public officer to perform a statutory duty would leave psychiatric survivors without sufficient legal remedy for the injuries to which they are particularly vulnerable. Moreover, laws infringing the liberty of persons with mental disorder had been upheld, in part, because courts recognized that these infringements were balanced by legal duties and other legally-prescribed protections.

Writing for a unanimous Supreme Court, Mr. Justice Iacobucci found no legal distinction between intentional abuse of power and intentional breach of duty giving rise to the tort of misfeasance of public office. The restrictions on the tort imposed by the Court of Appeal were overcome. Again, the position supported by the MHLC had been upheld.

Penetanguishene Mental Health Centre v. Ontario (A.G.) and Pinet v. St. Thomas Psychiatric Hospital

The MHLC returned to its core constituency in its interventions in two appeals heard together by the Supreme Court under the names of *Penetanguishene Mental Health Centre v. Ontario (A.G.)* (*Tulikorpi*) and *Pinet v. St. Thomas Psychiatric Hospital* (*Pinet*). These cases related to persons who were subject to orders of the Ontario Review Board after being found not responsible for criminal offences by reason of mental disorder. The common question of law raised in the appeals was whether the "least onerous and least restrictive" requirement of section 672.54 of the *Criminal Code*[6] (*Code*) applied only to the type of disposition (detention in a specific facility or conditional discharge) or to the conditions of detention, including the place of detention and security and privilege levels.

The Review Board panel in *Tulikorpi* determined that "appropriate" conditions of detention under the *Code* had to satisfy the same "least onerous and least restrictive" test as was applied to the disposition itself. The panel hearing the *Pinet* case reached the opposite conclusion. The Court of Appeal upheld the Review Board's decision in *Pinet* and reversed the decision in *Tulikorpi*. The accused persons appealed in both cases.

Together with MHLAC, its co-intervenor in the *Starson* case, the MHLC asserted that the Review Board's position in *Pinet* would invite the violation of the appellants' right to liberty under section 7 of the *Charter of Rights and Freedoms*[7] *(Charter)*. It noted in its written argument that while the "least onerous and least restrictive" requirement was recognized by the Attorney General as applying to different modes of detention, "any factor may govern the decision with respect to conditions." The appellants and, indeed, anyone committed to a mental health facility, would have no objective standards for the review of their conditions of detention.

The arguments of the appellants and the MHLC carried the day. On behalf of a unanimous Supreme Court, Mr. Justice Binnie upheld the appeals, deeming the least onerous and least restrictive test to be applicable to the disposition and to the conditions of detention, thereby eliminating any conflict with the appellants' *Charter* rights. In doing so, the Court established a more meaningful role for Review Boards to play in the reintegration of individuals under its jurisdiction into the community.

Braithwaite v. Ontario (A.G.)

The MHLC's next intervention was in a very different forum: two complaints heard together by the Human Rights Tribunal of Ontario. At issue in the complaints was whether subsection 10(4) of the *Coroners Act*,[8] which makes coroners inquests mandatory for deaths occurring in custody, contravened the discrimination prohibition in the Ontario *Human Rights Code*[9] by failing to require inquests into deaths occurring during psychiatric detention.

The complainants before the Tribunal were Renata Braithwaite, who lost her mother, and Robert Illingworth, who lost his brother, in fatal incidents while they were involuntary detained under the *Mental Health Act*.[10] Melba Braithwaite was found to have died of a heart attack after she fell in the shower at the Centre for Addiction and Mental Health, raising serious questions respecting access to medical care in psychiatric facilities. Thomas Illingworth died while chemically and physically restrained overnight at Humber River Regional Hospital. His cause of death could not be determined by the Coroner's office.

The Office of the Chief Coroner steadfastly refused to hold inquests into the deaths. The MHLC intervened at the Tribunal level jointly with the Empowerment Council (the successors to the Queen Street Patients Council) and the Psychiatric Patient Advocate Office. Intervening at the Tribunal rather than waiting to join in subsequent appeals presented the opportunity to call and cross-examine witnesses. The intervenors did both, contributing to a substantial record before the Tribunal.

Following a three-week hearing, the Tribunal, chaired by retired Supreme Court of Canada Justice Peter Cory, found for the complainants. In doing so, the Tribunal rejected government arguments that persons who are involuntarily detained should be treated by the Coroner's office in the same manner as patients who choose to be in hospital and are free to leave. The ruling did not amend the *Coroners Act*, but established that any future failure to hold an inquest into a death in psychiatric custody would be a breach of the *Human Rights Code*.

The Attorney General and the Chief Coroner appealed the decision to the Ontario Divisional Court, which rendered its decision reversing the Tribunal decision in December 2007. While accepting that inmates in jail were the appropriate comparator group for persons in psychiatric detention, the Divisional Court cited the psychiatric facilities' status as hospitals and found it unreasonable to mandate inquests from health institutions. The decision ultimately rests on the Court's conclusion that persons in psychiatric detention would not perceive the differential treatment of their deaths as an injury to their dignity.

At the time of writing, motions by the Commission and Renata Braithwaite for leave to appeal the Divisional Court's decision to the Ontario Court of Appeal are pending. The extensive evidentiary record on which the Tribunal based its decision, enhanced by the participation of the intervenors, bodes well for the ultimate outcome of any further appeal(s).

Conclusion

Much work lies ahead of the MHLC. Many barriers, legal and otherwise, continue to confront the constituency that it serves. To those sceptical that it will succeed, I offer the words of Margaret Mead, who once said, never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

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The author wishes to thank Carolyn Rock, a student in the University of Toronto Faculty of Law, who provided the research for this article through Pro Bono Students Canada.

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1 [2003] 1 S.C.R. 722.

2 [2003] 3 S.C.R. 263.

3 [2004] 1 S.C.R. 498.

4 [2004] 1 S.C.R. 528.

5 (2006), 56 C.H.R.R. 171 (H.R.T.O.), reversed under the name *Ontario (A.G.) v. Ontario (Human Rights Commission)*, [2007] O.J. No. 4978 (Div. Ct.); motions for leave to appeal to the Court of Appeal are pending.

6 R.S. 1985, c. C-46.

7 Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

8 R.S.O. 1990, c. C.37.

9 R.S.O. 1990, c. H.19.

10 R.S.O. 1990, c. M.7.

MENTAL HEALTH LAW AFTER THE CONVENTION

Peter Bartlett[*]

The United Nations *Convention on the Rights of Persons with Disabilities*

In December 2006, the General Assembly passed the new *Convention on the Rights of Persons with Disabilities.*[1] This is a notable event for a number of reasons.

First is the substantive content: where previous conventions had, at least implicitly, adopted an approach of rights tempered by paternalism, the new *Convention* focuses on social inclusion. A perusal of the subject matter of the articles gives a flavour of the approach:

- rights to accessibility (Article 9),
- right to life (Article 10),
- right to equal recognition before the law and access to justice (Articles 12 and 13),
- right to liberty and security of the person (Article 14),
- right to be free from torture and inhuman treatment (Article 15),
- right to freedom from exploitation and abuse (Article 16),
- right to integrity of the person (Article 17),
- right to liberty of movement and nationality (Article 18),
- right to independent living and community inclusion (Article 19),
- right to personal mobility (Article 20),
- right to freedom of expression (Article 21),
- right to respect for privacy (Article 22),
- right to respect for home and the family (Article 23),
- right to education (Article 24),
- right to health (Article 25), habilitation and rehabilitation (Article 26),
- right to work and employment without discrimination (Article 27),
- right to adequate standard of living and social protection (Article 28),
- right to participation in political and public life (Article 29), and
- right to participation in cultural life, recreation, leisure and sport (Article 30).

Throughout, the focus is on the full involvement of people with disabilities in broader society. The emphasis is on a non-discriminatory framework, and 'reasonable accommodation' of an individual's disability becomes a right, rather than an excuse for failure to provide services.

Second, the *Convention* establishes the UN Committee on the Rights of Persons with Disabilities. States party to the *Convention* will report to the Committee on their progress on implementation within two years of the *Convention* coming into force, and at least every four years thereafter. The Committee will in turn provide such comments as it sees fit on recommendations to the national government. It would be stretching matters to say that this constitutes an enforcement mechanism – the reports and decisions of the Committee will in the end be merely advisory – but it does follow that failure by countries to implement the terms of the *Convention* will be visible, both domestically and internationally.

Further, for states signing the Optional Protocol to the *Convention*, individuals who consider themselves victims of violations of the *Convention* will be able to make formal complaints for determination by the Committee. While Canada has signed the *Convention* itself, it has not, alas, signed the Optional Protocol: the government in Ottawa has decided that Canadians, unlike people in Croatia, Namibia, or El Salvador, for example, will not be able appeal to the Committee as individuals.

Finally, the process leading to the *Convention* involved much more extensive involvement of user groups themselves than has been the case in the past. This close involvement may say much about the substance that resulted: the user groups pushed for the rights that were meaningful to them. In any event, it has resulted in both a new confidence in disability rights advocacy organisations internationally as to what they can achieve, and an encouraging sense of ownership of the *Convention* by these groups.

The *Convention* will come into effect thirty days after ratification by the twentieth country, and the Optional Protocol thirty days after ratification by the tenth country. Currently,[2] there are 125 signatories to the *Convention* (including Canada), of which 17 have ratified (not including Canada). 71 countries have signed the Optional Protocol (not including Canada), of whom 11 have ratified the protocol. Presumably, both the *Convention* and Optional Protocol will come into effect soon.

The *Convention* has been viewed by many as a watershed event in international human rights in this area. This perception in part reflects how far disability rights have been marginalised in international law. Many of the rights provided by the *Convention* are reminiscent of the basic rights articulated for people in general in other UN documents such as the *International Covenant on Civil and Political Rights*,[3] the *Universal Declaration of Human Rights*,[4] and the *International Covenant on Economic, Social and Cultural Rights*.[5] It is distressing that the express extension of these rights to people with disabilities almost sixty years after the *Universal Declaration of Human Rights* is still perceived as a victory – but a victory it is perceived to be. Similarly, it would be astonishing for the negotiation of other UN conventions not to involve the people most directly affected by them; it is only right that people with disabilities should have been involved in the formulation of this *Convention*.

These advances are particularly clear for people with mental disabilities. Previous international instruments had either adopted a paternalist stance (e.g., the United Nations *Declaration on the Rights of Mentally Retarded Persons*)[6] or endeavoured to establish international standards for compulsory intervention in the lives of people with mental disabilities (e.g., United Nations *Principles for the Protection of Persons with Mental Illness*).[7] By comparison, the emphasis in the *Convention* is towards non-discrimination, supported autonomy and social inclusion.

For people with mental disabilities, the effect of the *Convention*, assuming it is implemented in Ontario and the rest of Canada, will largely be to buttress good practice and to make backsliding more difficult. Thus Ontario has policies to promote community living for people with mental disabilities. We may have concerns about the adequacy of those policies and their implementation, but they are there. The *Convention* provides a marker that failure to implement those policies properly renders Ontario below the standards expected in international human rights. In a country that prides itself on its tolerance and its exercise of human rights, a failure properly to implement the *Convention* ought to be a political embarrassment. There ought to be some rhetorical mileage for advocates in this regard, to press government to provide appropriate services.

The situation would be significantly strengthened, of course, if the government signed the Optional Protocol. It is all very well to require governments to submit reports every few years, but the best test of compliance is whether policies can be defended by people who actually feel aggrieved. Failure to sign the protocol suggests that our politicians want the photo-op, but are not prepared to defend their actions before a neutral tribunal in the face of the people most directly effected.

The *Convention* and Mental Health Law Internationally

The discussion of the *Convention* has in general focussed on its overall ethos. Little discussion seems to have occurred as to what it will mean for specific mental health law. Across the world, people with mental disabilities should benefit from the general provisions of the *Convention* – the right to integrity of the person (Article 17), for example. Even these apparently general rights may have meaningful effects if taken seriously. Thus the

Convention requires full human rights to be given to children with disabilities, on an equal footing with other children. It is to be hoped that this might trigger serious discussion of children with mental disabilities, who remain to a considerable degree outside the discourse of international human rights.

The nature of change will, of course, depend on the régime in question. The standards and approach of the *Convention* would imply extensive change to the approach to care in much of the world. In much of Asia, South America, and Africa, and indeed in much of central Europe, human rights for people with mental disabilities has remained off the political agenda. A few examples will provide a sense of how much the world still has to change.

Article 12 of the *Convention* provides people with disabilities a right to recognition as persons before the law, and a right to enjoy legal capacity on an equal basis with others in society. In much of central Europe, this does not currently occur: a finding of incapacity at law is plenary in effect, and removes a person's legal personhood. As a result, he or she will be unable to hire a lawyer to challenge decisions made ostensibly on his or her behalf, and will have no standing to challenge decisions of a guardian in court.[8] The determination of incapacity in these countries is often made on minimal evidence, resulting in people with mental health problems being denied legal personhood.

Article 15 provides the right to be free from torture or cruel, inhuman or degrading treatment or punishment. Once again, conditions in central Europe provide a reminder that basic standards of care cannot be assumed across the world. The reports of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) provide considerable evidence of good institutional standards in Europe, but also evidence of conditions little short of shocking. In a 2002 visit to a Bulgaria, for example, the CPT found the daily per capita allowance for food was less than half a Euro – something under 75 cents Canadian. The CPT noted a connection between the limited food and the mortality rate in the institution.[9] In much of central Europe, individuals remain kept in 'cage beds' – beds covered with metal or netted enclosures, precluding the individual from leaving the bed or indeed from standing up.[10] Article 15 further raises issues of inappropriate treatment. In a number of countries, Turkey for example, so-called 'unmodified' ECT is still practised; that is, ECT without anaesthetic or muscle relaxants.[11]

These examples are mere tasters of the sorts of issue that the *Convention* may bring to light. The examples are drawn from central Europe, because central Europe has begun – admittedly at a very rudimentary level - to engage with the issues. Central European countries have thus generally ratified the *European Convention on the Prevention of Torture*,[12] which provides jurisdiction for the CPT. Conditions in those countries are thus relatively well-documented. Conditions in other parts of the world are, it would seem, at least as grim.[13] It would of course be naïve to pretend that changes in attitudes in these countries will be instantaneous; but the *Convention* may expose officials in those countries to at least some of the thinking that has happened elsewhere regarding human rights and mental disability.

The *Convention* and Mental Health Law in Canada

The international situation serves as a reminder of how far Canada has come, and how much the work of advocacy organizations such as the Psychiatric Patient Advocate Office have meant in reforming law and policy regarding mental disability here. Article 25, for example, provides a right to provision of health care 'on the basis of free and informed consent.' For people with mental disabilities, this has been the law in Ontario for over 20 years, thanks to the early work of advocates (including those at the Psychiatric Patient Advocate Office) in the early 1980s. For most of the world, however, it is not the case: people with mental health difficulties are still treated over their competent objection. This is an area in which Ontario leads the way. Nonetheless, complacency would be inappropriate, and the standards of the *Convention* do raise issues for people in Canada.

Some specific substantive rights will be of particular relevance to people with mental disabilities. As a topical example, the right to independent living and being included in the community is created expressly by Article 19. It is difficult to see that this right is consistent with any return to large-scale institutionalization, and advocates may wish to make reference to the terms of the *Convention* when challenging large-scale new institutions, such as are currently under consideration in British Columbia. Internationally, it will, if actually acted upon, be of great significance, for in large parts of the world, large-scale institutions remain the primary method of state care of people with mental health difficulties or learning disabilities.

The *Convention* provides a non-discriminatory right to health care (Article 25). In much of the world, this will be of considerable significance, since mental health care is funded to a markedly lower degree than care for somatic disorders.[14] In Canada, as in so much of the world, quality of services is limited by available funding. The adoption of a non-discriminatory approach could introduce marked improvements in health provision.

The *Convention* provides a right to be free from exploitation, violence and abuse (Article 16). This serves as a reminder that people with mental disabilities are considerably more likely than the general population to be subjected to violence. It is fair to ask whether our society offers sufficient protection to people with mental disabilities to be free from this violence. This issue may overlap with the *Convention* right to an adequate standard of living and to social protection (Article 28). Many people with mental health problems live in public housing; but as the public housing stock is run down, it is fair to ask whether the existing accommodation is really appropriate for people with mental disabilities.

The *Convention* and the *Mental Health Act*

Article 14, concerning liberty and security of the person, will be more problematic to interpret in a mental health context. Along with the general right to liberty, similar to that contained in other human rights instruments, it provides that 'the existence of a disability shall in no case justify a deprivation of liberty.' (Article 14(1)(b)). This would seem to suggest that much of the existing Ontario *Mental Health Act*[15] is in violation. Ontario is not alone in this: it is difficult to see that any detention based on mental disability would be permitted, based on the wording of the article.

The fact that the Ontario act requires that a person be dangerous to themselves or others, or at risk of serious physical impairment, seems of little assistance here, as the detention is still justified by the mental disorder, in apparent violation of Article 14. The provisions further appear to conflict with the non-discrimination principle, contained in Article 5 and, implicitly, in much of the rest of the *Convention*. We do not lock up other people on the basis of prospective dangerousness, even when there is cogent statistical evidence of their dangerousness: why would we do so with people with mental disorder?

This opens a broad discussion about what mental health law is for, and when compulsion is justified. The approach of the *Convention* seems clear: no deprivation of liberty based on disability. Many advocates will have sympathy with this approach; but can it really be that simple? Care of people with severe dementia may well result in deprivation of liberty; are we ready to say that we allow these people to wander away from their place of care, in the name of rights? Perhaps one could argue for a capacity-based standard of confinement,[16] but it is not obvious that this avoids the problem: is it not sophistry to separate incapacity from the disability that causes the incapacity? And if so, deprivation of liberty based on incapacity is in effect deprivation of liberty based on disability – precisely what the *Convention* says we are not meant to do.

I would not wish to be perceived as arguing for the status quo on deprivation of liberty of those with mental disabilities, but it is not obvious that the simple abolition of mental health acts provides a solution either. It is perhaps more convincing to say that the *Convention* forces us to confront the paucity in our thinking about deprivation of liberty and mental disability. Until recently, it was taken as obvious that mental disability, perhaps combined with some criterion of severity, justified confinement. That premise, largely unspoken in the past, must be scrutinized. We may or may not end up abolishing mental health acts; but we will certainly need to become much more theoretically rigorous as to what they are for, how they are justified, and why the specific acts that we support are not inherently and inappropriately discriminatory.

Conclusion

The *Convention* is only a convention, and it remains to be seen whether it can meet the high hopes of disability rights advocates. While I hope the optimism is well-placed, there are reasons for scepticism. As the Commission will be international in jurisdiction, it will inevitably be forced to be somewhat general in its pronouncements. It will not be able to assume, for example, that all countries have the economic resources of Canada. As a result, it may well hedge its language in ambiguity, requiring the 'best attainable standards that resources reasonably allow,' for example. Indeed, for countries such as Canada not signing the Optional Protocol, it may be restricted to anodyne comments about reports constructed by civil servants to make their countries look good.

At the same time, the *Convention* does provide a marker in international law. Its terms and ethos will enter academic and policy literature, and will generate domestic debate and pressures for reform. On this level, the *Convention* surely represents an important step forward. It *is* different from the previous international instruments, and the introduction of its ideas into public discourse will stimulate change. That will not happen as fast as advocates want, and there will be considerable political wrangling ahead; but it provides a new base to work from.

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1 UN Doc A/61/611.

2 As of 4 March 2008.

3 G.A. res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171.

4 G.A. res. 217A (III), U.N. Doc A/810 at 71 (1948).

5 G.A. res. 2200A (XXI), 21 U.N.GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, *entered into force* Jan. 3, 1976.

6 G.A. res. 2856 (XXVI), 26 U.N. GAOR Supp. (No. 29) at 93, U.N. Doc. A/8429 (1971).

7 G.A. res. 46/119 (XLVI), (1991).

8 Regarding such provisions, see the reports regarding guardianship produced by the Mental Disability Advocacy Centre, available on line at www.mdac.info. These reports discuss guardianship in Hungary, Bulgaria, the Czech Republic, Russia and Serbia.

9 CPT/Inf (2004) 21 (visit of April 2002), para. 132-4. See report on Macedonia, CPT/Inf (2004) 29 (Visit of November 2002) para. 79 and report on Albania CPT/Inf (2003) 6 (visit of December 1997) paras. 21-27.

10 See MDAC, 'Cage Beds: Inhuman and Degrading Treatment in Four EU Accession Countries' (Budapest, MDAC, 2003), available on line at www.mdac.info. See also BBC documentary on this subject, available online at http://video.google.com/videoplay?docid=-9176914173325307126.

11 See Mental Disability Rights International, Behind Closed Doors: Human Rights Abuses in the Psychiatric Facilities, Orphanages and Rehabilitation Centers of Turkey (Washington: 2005), pp. 1-2.

12 ETS No 126..

13 See for example country reports of Mental Disability Rights International, www.mdri.org.

14 See World Health Organization, (2001). Mental Health: New Understanding, New Hope (World Health Report 2001). Geneva: WHO, 2001.

15 R.S.O. 1990, c. M.7.

16 See J Dawson and G Szmukler G. (2006). 'Fusion of mental health and incapacity legislation.' *British Journal of Psychiatry* 188:504-9.

THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND ITS IMPACT ON THE RIGHTS OF INDIVIDUALS WITH MENTAL ILLNESS IN ONTARIO

Joaquin Zuckerberg[*†]

The end of the Second World War and the creation of the United Nations, its *Charter*[1] and associated *Universal Declaration of Human Rights*[2] marked a turning point for the international human rights movement. However, mental health was and continues to be remarkably absent from the work of international human rights organizations and non-governmental organizations (NGOs). In other words, mental health law has not kept up with the significant development of political and (to a lesser degree) social and economic rights, as may be seen from the number of international treaties, declarations, publications and human and institutional experts. No doubt this disparity was fuelled by the international political situation after the War which gave primacy to certain views of what human rights constituted. Nor can one ignore modernity's exclusionary effect of the "other" from the rights discourse. Finally, the very vulnerable position of the mentally ill has placed them in a more difficult position from which to make their voices heard. Unsurprisingly, the first reports of human rights abuses reported by international NGOs only referred to political dissidents in psychiatric facilities in the former Soviet Union, but not to abuses against other patients.[3]

International Instruments

There are several documents dealing directly or indirectly with people with disabilities. However, most of them are rarely used, non-binding and ambiguous in their wording. The most relevant to the mentally ill are the *International Covenant on Civil and Political Rights* (*ICCPR*), the *International Covenant on Economic, Social and Cultural Rights* (*ICESCR*) and the UN *Principles for the Protection of Persons with Mental Illness* (the *Principles*). The *ICCPR* and *ICESCR* do not mention "mental illness" (or even "disability") as a protected category, but this protection is found by implication.[4] The *Principles* are non-binding and provide standards for treatment and living conditions within psychiatric institutions and create protections against arbitrary detention in such facilities. There are also regional supranational instruments such as the *European Convention for the Protection of Human Rights and Fundamental Freedoms*[5] (e.g., Article 5 deals with the deprivation of an individual's liberty) and the newer but significantly less used *Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities*.[6]

The Convention

The purpose of the *Convention on the Rights of Persons with Disabilities*[7] (the *Convention*) "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."[8] Persons with disabilities include those who have long-term mental "impairments" which "in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[9] The *Convention* is therefore the first international *binding* instrument which *expressly* applies to people who have a mental disability. The *Convention* reinforces the view of people with disabilities as rights holders, who are often disabled by physical and attitudinal barriers erected by societies.[10]

Given space constraints, I will only mention some of the most significant provisions vis-à-vis Ontario. There are a number of "positive" clauses which require the government to provide access to "community support services,"[11] "habilitation and rehabilitation services,"[12] "awareness-raising" measures[13] and other "public health programmes."[14] These may become an important tool for those who seek further funding for certain areas of health care dealing with the mentally ill.

Ontario mental health legislation appears to have addressed the rights enumerated in the *Convention* dealing with the protection of the liberty and integrity of a person.[15] However, the wording of a number of these provisions raises some interesting questions.

Article 12(5) ensures that persons with disabilities are not arbitrarily deprived of property, and describes "property" in a flexible, multi-faceted manner (e.g., mortgages, loans, inheritance, and control of financial affairs). This appears to embrace a task-based model of incapacity (i.e., incapacity based on the ability to fulfil a specific task) that Ontario adopted for treatment incapacity but rejected for incapacity to manage property. In effect, Ontario's rigid model of incapacity regarding property which may result in an absolute all-inclusive guardianship appears to run afoul of the spirit, if not the letter, of the *Convention*.

Article 15(1) bans "medical" or "scientific" experimentation without free consent. This is perhaps one of the most noteworthy provisions, given the absence of Ontario legislation or comprehensive federal regulation in this area. The recently constituted Mental Health Commission of Canada may take notice of this provision if it is to make recommendations to fill this legislative gap.[16]

Under article 22 of the *Convention*, States Parties must protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others. The use, access and disclosure of personal health information is regulated in Ontario through a number of legal instruments, including the *Personal Health Information and Privacy Act*.[17] Nevertheless, the current practice of some Ontario police services, which record information about incidents arising from the transportation of individuals to hospitals for a psychiatric evaluation under the *Mental Health Act*, may be inconsistent with the equality provisions of the *Convention*. The retention of this information by police forces may limit the ability of an individual to gain employment whenever the employer requires a police reference check.

Under the *Convention*, States must set up national focal points for governments in order to monitor implementation of the *Convention's* precepts. States must also set up some sort of independent monitoring mechanisms – which usually take the form of an independent national human rights institution. International monitoring is achieved via the Committee on the Rights of Persons with Disabilities (the Committee) and the Conference of States Parties. States Parties will provide reports to the Committee every two years after the Convention has entered into force. The reports will provide a comprehensive explanation of the progress made towards implementation of the *Convention*. Under the Protocol, a State Party recognizes the competence of the Committee to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the *Convention*.

It is premature to assess whether the *Convention* will have a significant effect on the mentally ill in Ontario and in Canada generally. First, the *Convention* and Protocol will only enter into force once twenty countries ratify it. As of January 2008, only 14 had ratified the *Convention* and 8 had ratified the Optional Protocol. Second, Canada has signed but not ratified the *Convention*. As human rights is a matter of shared federal-provincial jurisdiction, the general practise in Canada is to only ratify a human rights treaty after obtaining the support of Canadian provinces and territories. This is a time-consuming process which is subject to the political agenda of the government of the day. Third, international law does not become part of Canadian law once it is ratified until it is incorporated into domestic legislation (i.e., through legislative action). Nonetheless, international treaties, even if not incorporated, can serve as an important interpretive tool for domestic legislation and the Canadian Constitution.[18] Additionally, it is expected that the Mental Health Commission of Canada will consider the *Convention* to measure legislative compliance with international human rights standards.[19]

The final hurdle that must be considered is the fact that Canada has not signed the Optional Protocol. This means that a complainant will not be able to access the Committee regarding an alleged violation even if Canada ratifies the *Convention* and incorporates the *Convention* through legislation.

Conclusion

It is hard to assess the impact of the *Convention* in Ontario at this early stage. The *Convention's* major impact is likely to be felt in countries with limited or no legislation in the area and less so in Canada which features relatively sophisticated mental health and human rights legislation. Furthermore, without further political and legislative action, the *Convention* will only remain as a guiding tool, though a significant one, for policy makers in Ontario. Therefore, two of the *Convention's* key contributions to Ontario in the near future are its ability to raise awareness and influence both the federal and provincial political agenda. It remains to be seen whether successful advocacy will bring this about.

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[†] Any views or opinions expressed in the article are those of the author and do not represent the views of the Consent and Capacity Board.

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1 June 26, 1945, 59 Stat. 1031, T.S. 993, 3 Bevans 1153, *entered into force* Oct. 24, 1945.

2 Adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948

3 Amnesty International only involved itself with non-political patients in Bulgaria in 2001. *See Bulgaria: Disabled woman condemned to 'slow death'.* EUR 15/002/2001, 10/10/200; *Bulgaria: Cruel, inhuman and degrading treatment, Women inmates at Sanadinovo*, EUR 15/001/2001, 10/10/2001 and *Bulgaria: Sanadinovo: "This is truly a ghastly place"*, EUR 15/002/2002, 11/04/2002. Available on http://asiapacific.amnesty.org/library/eng-bgr/index&start=31.

4 See Zuckerberg, J., "International human rights for mentally ill persons: The Ontario experience", *International Journal of Law and Psychiatry* 30 (2007) 512–529.

5 213 U.N.T.S. 222.

6 Canada has not signed the Inter-American Convention, nor has it signed the more general American Convention on Human Rights ("Pact of San Jose, Costa Rica").

7 G.A. res. A/61/611, 2006.

8 Art. 1.

9 Art. 1.

10 Kanter, Arlene S., "The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities," *Syracuse Journal of International Law and Commerce;* Spring 2007; 34, 2; 287 at 291.

11 Art. 19.

12 Art. 26.

13 Art. 8.

14 Art. 25.

15 Arts. 15, 12, 13 and 14 deal with unlawful or arbitrary detention and art. 17 with the protection of an individual's integrity. Article 25 requires the *right to informed consent to medical treatment.*

16 The Commission is a non-profit organization created to focus national attention on mental health issues and to work to improve the health and social outcomes of people living with mental illness.

17 S.O. 2204, c. 3, Sch. A.

18 *Reference Re Public Service Employee Relations Act (Alta.)*, [1987] 1 S.C.R. 313.

19 Measuring up compliance with international human rights instruments is not an unfamiliar exercise for national bodies in charge of national mental health policy as shown by the experience of the Australian National Mental Health Strategy.

THE ROLE AND FUNCTION OF THE CONSENT AND CAPACITY BOARD IN THE MENTAL HEALTH SYSTEM - ISSUES AND TRENDS

Justice Edward F. Ormston[*]

Role and Function:

Many people suffering from a mental illness find themselves detained in a psychiatric facility without their consent, sometimes for long periods of time. It is noteworthy that the *Mental Health Act*[1] gives physicians greater power to detain people than those afforded to the police.

The Consent and Capacity Board (Board) is the quasi-judicial body established under the *Health Care Consent Act*[2] to provide reasonable safeguards to a person's right to life, liberty and security of the person and to ensure these rights are not restricted except in accordance with the principles of fundamental justice. The Board provides an independent, unbiased tribunal that determines if a physician has followed all the legal and procedural requirements set out in the *Mental Health Act* for such detention. The Board balances an individual's right to life, liberty and security of the person against society's right to safety and security. It is all about balance – with autonomy and liberty on one hand and treatment, protection and public safety on the other hand.

The Board also reviews health practitioners' findings of incapacity to manage one's property. It reviews a young person's admission as an informal patient to a psychiatric facility. The Board also reviews a health professional's finding that a person lacks the capacity to consent to treatment, admission to a care facility, or a personal assistance service, and hears applications seeking the appointment of representatives to make decisions on these issues.

This is the majority of the Board's work, although it also has responsibilities under the *Substitute Decisions Act*[3]; the *Personal Health Information Protection Act*[4] and the *Health Protection and Promotion Act*[5] (which requires the taking of blood samples to protect victims of crime, emergency service workers etc.).

Issues and Trends

Upon my appointment as Chair of the Consent and Capacity Board, a strategic assessment was conducted in respect to how the Board was functioning and how it was perceived.

The feedback received from a cross-section of stakeholders revealed a number of problems.

Patients complained that:

a) hearings were frequently cancelled;

b) they did not feel they got an opportunity to be "heard" by an independent tribunal;

c) lawyers were being forced on them by the Board when they wished to represent themselves;

d) Patient Advocates from the Psychiatric Patient Advocate Office could not attend the hearings with them; and

e) they felt generally "left out" of the process.

Many doctors were frustrated by the Board for the following reasons:

a) the scheduling was often inconvenient especially for fee-for-service practitioners;

b) the notice given before a hearing was too short;

c) they were unrepresented by counsel;

d) the patients counsel were sometimes rude, aggressive and unprepared;

e) Board members did not sufficiently control the process;

f) Rights Advisers from the Psychiatric Patient Advocate Office refused to advise doctors when patients requested a CCB hearing; and

g) the hearings were too "legalistic" and adversarial, which threatened their therapeutic alliance with their patient.

The patients' lawyers expressed opinions that:

a) the Board members did not understand the legislation;

b) the Board members and health practitioners did not understand the role of the patients' lawyers; and

c) the Board members were insensitive to the patients' needs.

The Board members expressed opinions that:

a) doctors were often hostile and did not understand the role of the Board or the patient's lawyer;

b) patients' lawyers were not uniformly well trained;

c) the physical accommodation provided for the hearings within hospitals was unsuitable; and

d) the general public did not know the Board existed.

To address these issues, the Consent and Capacity Board has undertaken several projects.

a) Appointment Issues

We have set up a more vigorous screening process for prospective members. Applicants are interviewed by a panel of current sitting members, and asked to prepare sample reasons for a decision based on a hypothetical set of facts.

Once appointed, new members are assigned an experienced mentor to assist them. They participate in training panels until they are found to be ready to sit on regular panels.

b) Ongoing Member Training

The structure of a hearing and the appropriate conduct of Board members is part of the mandatory training at every education session. We are also working on creating a template for Board members for the reasons of decision in order to standardize the format.

c) Our in-house education program is now more diverse and hears representatives from various points of view.

d) We have established a Board and Bar Committee, consisting of counsel from the hospital and defence bar, as well as representatives of the consumer-survivor community and the Ministry of Health and Long-Term Care, which meets regularly to discuss mutual concerns.

e) In order to provide consistency on contentious issues which arise frequently, we have established policy guidelines to provide predictability and clarity until a judicial opinion on the issue is obtained.

f) Public Education Issues

I. The Board, after consultation with the medical profession and the concurrence of the Board and Bar Committee, has prepared a template for doctors to be used at hearings which outline the essential elements that the legislation requires (the "CCB Summary Template"). We hope this will create shorter, more focused and less adversarial hearings. We have a team from the Board that attends at hospitals to explain the template and to receive feedback on this initiative.

II. We present at Grand Rounds throughout Ontario on end of life issues and the legal process involved in removing a patient from a respirator.

III. We are engaging the medical, nursing, and social work faculties within Ontario universities to assist in preparing curriculum that will introduce future practitioners to the Consent and Capacity Board's role and responsibilities.

IV. The Board has partnered with various groups and has produced videos that demonstrate how hearings are conducted. These videos are available to any interested group.

V. The Board is very interested in providing public education to interested groups and will provide speakers. We encourage people to make their own end of life decisions. Do they have a power of attorney for personal care? Have they appointed a substitute decision maker? Do they want to be on a respirator? For how long and under what circumstances?

g) As Chairman of the Board, I am concerned that the process be as user-friendly as possible. An adversarial process does not have to be rude or demeaning. We are exploring a mediation process that may resolve some applications without the need for a hearing, and the strain on the therapeutic alliance that sometimes results.

In summary, the work of the Consent and Capacity Board will continue to increase as the aging "baby boomers" confront issues around legal capacity. Ontario has the "Cadillac" of models within Canada on how to deal with these issues, but the car may be too big for the road. The legislation that governs the Board is a hodgepodge of a variety of statutes that should be consolidated into one.

We are anxious to share our knowledge and assist in eliminating the problems that arise, while maintaining our role of protecting personal rights through an independent hearing in accordance with the principles of fundamental justice.

*Justice Edward F. Ormston is the Chair of the Consent and Capacity Board, a quasi-judicial administrative tribunal which reviews issues under various Ontario health statutes.

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1 R.S.O. 1990, c. M.7.
2 S.O. 1996, c. 2, Sched. A.
3 S.O. 1992, c. 30.
4 S.O. 2004, c. 3, Sched. A.
5 R.S.O. 1990, c. H.7.

THE ROLE AND FUNCTION OF THE ONTARIO REVIEW BOARD IN ONTARIO'S MENTAL HEALTH SYSTEM

Joe Wright*

The members of the Ontario Review Board (ORB) and staff would like to extend congratulations to the Psychiatric Patient Advocate Office (PPAO) on celebrating its 25th year promoting the rights of those citizens with mental illnesses, and of advocating on their behalf.

The PPAO has not only contributed to the persons that they serve and aid, but to the other partners involved in the mental health system of the province. The ORB is grateful for the work that the PPAO has performed and the assistance that they have given the Board.

The ORB remains a fixture of the forensic mental health system of the province, and its mandate is set out in the *Criminal Code of Canada.*[1] Every person who comes under the jurisdiction of the ORB does so because they have been charged with a *Code* offence.

The duties and responsibilities of a Review Board are contained within a discrete chapter of the *Code,* Part XX.1. While the criminal justice system remains a dull instrument to deal with issues that are frequently rooted in social problems and poverty, the introduction of Part XX.1 represented a major advance in extending fairness to those with mental disorders caught up in the criminal justice system and represents one of the major changes that the PPAO has experienced since its inception.

Part XX.1 of the *Criminal Code*

All persons who receive a verdict in court of "unfit to stand trial due to a mental disorder" (unfit) or "not criminally responsible due to a mental disorder" (NCR) on criminal charges come under the jurisdiction of the ORB. The scheme which governs their supervision is Part XX.1. While the PPAO does not represent accused persons at hearings, any one of those persons may turn to the PPAO for assistance.

The Supreme Court of Canada (SCC) struck down the former, insanity provisions of the *Code* on constitutional grounds in 1991.[2] The new scheme, which was introduced to govern those individuals found unfit or NCR, modernized some of the language that had been used in the *Code* for over 100 years. For example, the term "not guilty by reason of insanity" was changed to "not criminally responsible on account of mental disorder." More importantly, these new mental disorder provisions aimed at providing fairness to the accused individual, and the least interference in a patient's life that was consistent with public safety.

For Review Boards, the obligations and duties of carrying out Part XX.1 were confirmed and clarified in 1999 with the release of the SCCs decision in *R. v. Winko.*[3] The court found that the scheme as set out in Part XX.1 was constitutional.

They did so on the basis that any time a review board makes or reviews a disposition in respect of an accused person they must positively conclude that individual at that time represents "a significant threat to the safety of the public." There is no presumption that the individual whose hearing is proceeding represents a significant threat and therefore no onus on the individual to prove otherwise. Evidence must be heard to permit the Board to positively conclude that an accused person is a significant threat. If the Board is uncertain or unsure, that person is entitled to an absolute discharge. And, the court found "significant threat to the safety of the public" means a real risk of physical or psychological harm to members of the public which is serious in the sense of going beyond the merely trivial or annoying. The conduct giving rise to the harm must be criminal in nature.

To panels conducting a hearing, a past offence committed while the NCR accused suffered from a mental illness is not, by itself, evidence that the individual continues to pose a significant risk to the safety of the public. Under Part XX.1 the focus of any hearing concerns the current circumstances of the individual, and that person's prospects for the coming year.

Under the former insanity provisions, a person found not guilty by reason of insanity was automatically detained in strict custody "at the pleasure of the Lieutenant Governor." Automatic strict custody was eliminated in Part XX.1. Instead, the court was empowered to hold a disposition hearing immediately following a verdict of not criminally responsible and to make its own disposition for the accused.[4] The possible dispositions include an absolute discharge, a conditional discharge or custody in a hospital.

As a result of amendments passed by Bill C-30 to Part XX.1, a number of changes became effective in June 2005 and January 2006. The initial changes were largely inspired by the Supreme Court of Canada's decision in the case of *R. v. Demers*[5] where it ruled that the absence of a mechanism to absolutely discharge an accused person with a verdict of unfit to stand trial could not pass constitutional scrutiny.

Amendments to the *Code* effective June 30, 2005 allowed Review Boards to make a recommendation to a court that an individual's charges be stayed, or withdrawn, when a person who was found unfit to stand trial was considered to be permanently unfit and no longer a significant threat to the safety of the public.

As well as a procedure to refer those persons back to court, those amendments provided Review Boards with a codified power to order assessments in support of that, and at the same time authority to order assessments of other accused persons in circumstances where it was necessary.

The amendments which became effective January 2, 2006, contained a number of other provisions. Perhaps most conspicuous were those amendments which created an obligation on a Review Board to provide notice to the victims of any index offence, both at the time an initial hearing proceeded, and when it appeared that an accused person might be entitled to a conditional or absolute discharge.

Legal uncertainty about when the obligation arose, and lack of information concerning the identity of victims and how to locate them, sometimes after the passage of many years, resulted in adjournments and delays which inconvenienced accused persons and concerned the ORB. Through efforts made by the ORB and an initiative of the Attorney General's office, and the passage of time, it appears that this problem has largely been rectified.

Other January 2006 amendments made procedural changes, but included the repeal of proposed sections which would have limited the amount of time an accused person could be subject to the jurisdiction of a Review Board ('capping') and introduced a section which, under some circumstances, would allow a Review Board to extend the time within which an accused person's disposition was reviewed from annually to 24 months.

Review Board Hearings

Review Board hearings are open to the public, subject to the Board's discretion to exclude the public, where it considers it to be in the best interest of the accused person and not contrary to the public interest. The courts have indicated that only in a rare case will this be justified.

In Ontario, most, hearings are held in the hospital where the accused person is detained or required to report. In the last 12 months, the ORB has held approximately 1650 hearings for the 1359 accused persons under the Board's jurisdiction.

While the Board is always mindful that the liberty of an individual is the focus of any hearing, and that an index offence exists, it is a matter of some concern that participants in hearings continue to view them as trials.

Section 672.5(2) of Part XX.1 suggests that Review Board hearings should be conducted in as informal a manner as is appropriate in the circumstances. For instance, when an ORB hearing is conducted in a hospital, it is usually held in a boardroom or other similar setting. Evidence may be, but rarely is, taken under oath. *Winko* and other court decisions have stated that unlike a trial, hearings are not adversarial. Courts have observed as well that although some hearings may prove to be contentious, and that the adversarial model is one that is familiar to participants in the Review Board process, it is not the model selected by Parliament for arriving at the most appropriate disposition.

Unlike a trial, which is focussed upon establishing the facts of an event which occurred at a fixed event in the past, a hearing to review a disposition is concerned with the state of affairs as it presently exists, and which looks forward to contemplate the least onerous and least restrictive disposition for the accused person.

Unlike a trial, if the parties do not present sufficient information, it is up to the court or Review Board to seek out the evidence it requires to make its decision. The courts continue to remind the ORB of its responsibility to be inquisitorial in seeking out the necessary evidence. Regardless of the source of the evidence, there is never any legal burden on the NCR accused to show that he or she does not pose a significant threat to the safety of the public.

Recent Caselaw and Issues

The SCCs 2006 decision in *Mazzei v. British Columbia (Director of Adult Forensic Psychiatric Services)*[6] confirmed the ability of a Review Board to bind other parties than the accused in a disposition, especially Hospitals, their directors and treatment teams. The scope of a Review Board's power to make orders and attach conditions in respect of medical treatment of accused persons would arguably include anything short of actually prescribing that treatment be carried out by a hospital, the court found.

Recent court decisions[7] continue to uphold the right of accused persons to be transferred from one hospital to another in a timely fashion. The fact that delays in transfer continue to occur can result in delay for accused persons achieving their and the legislation's goal of an absolute discharge.

Appeals from dispositions of the ORB are made directly to the Ontario Court of Appeal, and in the course of dealing with the appeals, the court scrutinizes matters both procedural and substantive. The Board's practices continue to evolve to reflect the guidance that that court provides.

The Ontario Review Board congratulates the Patient Advocates office on its valuable contribution to their clients and the province's mental health system, and looks forward to their participation in the next 25 years.

* Joe Wright is legal counsel at the Ontario Review Board.

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1 R.S., 1985, c. C-46.
2 *R. v. Swain*, [1991] 1 S.C.R. 933.
3 [1999] 2 S.C.R. 625.
4 Part XX.1 uses the term "accused" when referring to persons who have been found unfit to stand trial or not criminally responsible for an offence on account of mental disorder.
5 [2004] 2 S.C.R. 489.
6 [2006] 1 S.C.R. 326.
7 *Pinet v Mental Health Centre, Penetanguishene* (2006) CCC (3rd) 116.

ROLE OF THE PUBLIC GUARDIAN AND TRUSTEE: EMERGING ISSUES AND TRENDS IN PUBLIC GUARDIANSHIP

Louise Stratford* and Trudy Spinks**

The Office of the Public Guardian and Trustee ("OPGT") and the Psychiatric Patient Advocate Office ("PPAO") serve many of the same clients. Approximately 65% of the individuals for whom the OPGT is appointed as guardian of property have been, or continue to be, users of mental health services. Similarly, a high percentage of the referrals to our Treatment Decisions Unit are made for people who are receiving psychiatric treatment. Both of these groups are also served by PPAO staff in their capacity as rights advisers and patient advocates. As a result, the OPGT and the PPAO, despite having different mandates, have many areas of common interest. We are therefore appreciative of the opportunity to contribute to the PPAO's 25th anniversary publication by providing some observations and commentary about a few of the emerging issues and trends in public guardianship.

Serving the Independent Client

It is becoming increasingly common for individuals who are assessed as incapable of managing finances, and for whom OPGT acts as guardian of property, to continue to live independently in their own homes. In many cases these clients – often middle aged or elderly – have grown up in these homes and have never lived anywhere else. When the last surviving parent dies or moves to long-term care the OPGT is called in and assigned responsibility for the client's finances, including the management of their real property. The OPGTs approach to the management and maintenance of the real property may differ radically from that of the client's parents in previous times, and now the client.

As a trustee, the OPGT is mandated, wherever possible, to maintain real estate assets to a high standard by complying with building code requirements and fire and safety regulations and by making repairs as necessary and affordable by the client.

Clients, on the other hand, are often suspicious of any type of government intrusion and oppose any involvement by the OPGT especially in relation to their home and personal surroundings. They generally do not understand or appreciate the objectives and obligations of a trustee or the potential loss of value through disrepair. As a consequence, they often reject efforts to inspect or maintain the property. Physical access to the property is often refused. Attempts to press the issue usually only serve to exacerbate the client's emotional distress and create a different type of risk – risk to the client's already fragile state of health. This tends to be an even greater issue when the client has been "hoarding" and the OPGTs intervention is seen as a threat to these personal possessions.

When clients refuse access, the OPGT must weigh its financial obligation as trustee against its obligation to respect the client's residential and lifestyle choices and avoid causing severe mental and emotional distress. It must be noted that the client retains his or her right to decide where and how they live and that the OPGT, as financial guardian, cannot override these choices.

When faced with this issue and after consideration of all less intrusive avenues to obtain voluntary access, the OPGT is faced with evaluating – on a case by case basis – whether forced entry to the property including, in some cases, physically removing the client from his or her home on a temporary basis, is justifiable in the particular circumstances. Many factors go into making this decision including information that may be obtained from third parties such as relatives and friends, what is known about the condition of the property through other sources, the client's past history and degree of resourcefulness and the client's financial ability to fund repairs. If a decision is made to force access, the OPGT will first seek a court order allowing it to do so with police assistance. The courts have traditionally been very cognizant of the need to respect the client's rights and only issue such orders sparingly and with many terms and conditions attached.

The increasing prevalence of condominium ownership has raised unique concerns as well. Frequently, other residents of the building will look to the OPGT to address a client's hygiene or behavioural issues that are impacting on them. They often have difficulty understanding or accepting that the OPGTs sole mandate is to protect and advance the financial interests of the client and his or her dependents. Providing the client's financial obligations to the condominium corporation are in good standing, the OPGT is not mandated to assist them. In fact, the OPGTs obligation to the client requires that we ensure that his or her legal rights are protected and that they have access to legal representation if any steps are taken toward eviction.

Serving the Mobile Client

It is becoming increasingly common for financial guardianship clients to move away from Ontario. The OPGT currently has over 300 clients who reside outside of Ontario and many of them reside outside of Canada. From a legal standpoint, the OPGT continues to be responsible for the financial affairs of these clients indefinitely. Guardianship authorities in the other jurisdictions may not wish to seek authority or may have legal and/or medical mechanisms for the appointment of a guardian that are very different from Ontario's.

Managing money and property from afar is not, of course, impossible in this era of electronic banking, e-mail and faxes. There are, however, significant components of the guardian's job and the guardian/client relationship that are compromised by issues of distance. OPGT staff cannot, for example, visit the client to verify whether accommodations or other services that we are paying for on the client's behalf represent value for money or are even being provided to the client. Clients who wish to regain control of their finances do not have access to the Ontario capacity assessment and/or review processes that are required in normal circumstances to terminate guardianship. Language differences often present significant difficulty in conducting business on the client's behalf. Foreign institutions and authorities are usually unfamiliar with the legislation surrounding guardianship appointments in jurisdictions other than their area and many refuse to deal with our office as the client's representative.

It should also be noted that unlike financial guardianship, where our authority is solely for management of finances and continues regardless of the client's location, any responsibilities the OPGT may have for personal care decisions such as treatment decision making end at the Ontario border. Outside Ontario, these matters are governed strictly by the laws of the new jurisdiction to which the client has moved.

In Canada, significant efforts are being made to streamline interaction between provincial guardianship bodies with a view to promoting the transfer of property guardianship responsibilities, wherever possible, when this protection continues to be needed by the client. Dealing with the issue outside of Canada remains problematic.

Addressing the Concerns of Family Members

It is generally believed that the OPGT is only involved as guardian of property or treatment decision-maker for incapable adults who have no family. This is, in fact, not the case anymore. The majority of the OPGTs clients do have relatives such as siblings, children or parents. In a few instances, these family members have been acting for the client, or wish to act, but are considered unsuitable for this responsibility due to concerns about abuse, exploitation or lack of ability. More typical, however, is the family's lack of interest in assuming the very onerous responsibilities of a guardian or health care decision- maker.

Either way, the OPGT often finds itself – more often in the context of financial management than in health care decision-making – in a situation where relatives are actively involved with the client and have strong views about what steps the OPGT should, or should not take, with respect to the client's money or other assets. This can lead to conflict, particularly when certain steps – such as entering to inspect and value a home, safeguarding the client's interest in a joint bank account or redirecting the client's income cheques or benefits – must be performed in order to meet a guardian's legal obligation to safeguard the client's financial resources. Education of, and communication with, the family at the outset of the guardianship is vital in order that the family members understand that the OPGT must, by law, take certain steps, regardless of the wishes of the family. The OPGT does make efforts to communicate with relatives but the level of opposition to our involvement means that families sometimes resist these efforts.

Another common scenario involves family members who are in severe conflict with one another over the client's property and who look to the OPGT to take a "side" in the matter. Concerns about the security and magnitude of a potential inheritance are also prevalent. As a result, expenditures which may be viewed by the OPGT as warranted for the enhancement of the client's quality of life may be viewed by the relatives as wasteful and/or not in keeping with a client's previously frugal lifestyle.

Notwithstanding these pressures, the OPGT is committed to making only those decisions that are in the *client's* best interest. The input of relatives is necessary and valuable but the OPGT, like any trustee, must take great care to properly evaluate the information it receives and guard against compromising the client's financial interests in order to satisfy the financial interests of family members. Fortunately, there are many instances in which the family's interests can be accommodated within the scope of the OPGTs duty to its client and, wherever possible, these "win-win" solutions are sought.

Finally, the OPGT continues to promote the right of supportive family members and friends to seek guardianship appointments by applying to our Office or the court for such an appointment. The effect of such an appointment would be to transfer decision making from the OPGT to the appointed family member.

Resource Materials:

The foregoing is a brief overview of only a few of the emerging issues and trends in public guardianship. For a more comprehensive description of the OPGTs roles in serving incapable adults, the reader may wish to access the following guides and brochures, including:

- "Guide to the *Substitute Decisions Act*"
- "When the Office of the Public Guardian and Trustee Becomes Your Guardian of Property"
- "Guardianship Investigations"
- "Providing Property Guardianship Services"
- "Becoming a Guardian of Property"
- "The Role of the OPGT in Making Substitute Health Care Decisions"
- "Powers of Attorney and Living Wills – Some Questions and Answers"
- "Capacity Assessment Office"
- "Powers and Duties of a Guardian of Property"

Copies of these can be obtained by calling the OPGT information request line at 416-326-1353 or on the OPGT website at: www.attorneygeneral.jus.gov.on.ca/english/family/pgt/ .

*Louise Stratford is the Public Guardian and Trustee.

** Trudy Spinks is the Deputy Public Guardian and Trustee/ Client Services.

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LEGAL AID ONTARIO – PROVIDING ACCESS TO JUSTICE FOR INDIVIDUALS WITH MENTAL ILLNESS

Heather Morgan* and Rob Buchanan**

Legal Aid Ontario (LAO) has a statutory mandate to provide high quality legal aid services to low-income individuals in Ontario. It is proud to provide access to justice, in the form of legal advice, assistance and representation, to over one million low-income persons in this province each year. Many of the clients that LAO assists are persons with mental health issues.

LAO has a specific statutory directive to provide mental health law services. Section 13(1) of LAO's governing statute, the *Legal Aid Services Act*,[1] provides that:

> 13. (1) The Corporation shall provide legal aid services in the areas of criminal law, family law, clinic law and mental health law.

At LAO, providing mental health law services does not mean concentrating our services in one distinct area. Individuals who are living with mental health issues often experience interrelated legal problems, including criminal, housing, income support, disability and others. It is important for LAO to provide the best possible client service by being able to recognize where a connection exists between mental health issues and a client's other legal problems. It is an unfortunate truth that persons with mental health issues often find themselves involved with the legal system, and particularly with the criminal justice system, because other systems have already failed them. The courts represent the last opportunity they may have to be heard, and to receive justice.

Understanding that this is a particularly vulnerable client group with special needs, LAO has made providing service to the mentally ill a priority, and offers services in a number of areas. While there are limits to the coverage that LAO can provide, LAO's policies on provision of services to individuals experiencing mental illness have been drafted as liberally as possible.

LAO's core methods of providing client service are through its certificate program (where members of the private bar accept certificates authorizing the provision of legal services, from eligible clients), its duty counsel program (which provides advice and in-court representation for otherwise-unrepresented persons, mainly in the areas of criminal and family law) and the legal clinic system (which is comprised of 80 LAO-funded clinics and six Student Legal Aid Service Societies located across the province). Legal clinics and Student Legal Aid Service Societies provide widely varied services mainly in the sphere of so-called "poverty law," with a primary emphasis on housing and income security issues.

Through its certificate program, LAO provides services to clients with mental health issues in civil mental health proceedings as well as in criminal proceedings.

In the area of civil mental health law, LAO issues certificates for representation before the Consent and Capacity Board (CCB) concerning issues under the *Mental Health Act*[2] or under the *Health Care Consent Act*.[3] Applications for legal aid for these issues are often taken directly at a hospital by a rights adviser. The kinds of matters that LAO provides coverage for include:

- challenging a physician's certificate of involuntary admission or certificate of renewal;
- challenging a determination that a patient is not capable of consenting to treatment, or of being able to examine or authorize disclosure of a clinical record, or to manage his or her estate;
- reviews of informal admissions of a child aged between 12 and 15 years;
- applications by physicians to the CCB to overrule a patient's previous competent instructions contained in a power of attorney for personal care; and
- challenging the issuance or renewal of a community treatment order and plan.

LAO has adopted a policy that supports timely legal representation for individuals appearing before the CCB. The timelines for holding proceedings before the CCB are short (within seven days of the request for a hearing), and legal aid area offices are directed to decide quickly about whether to issue a certificate to an applicant. LAO's financial eligibility testing rules are applied leniently to these applications. LAO wants to encourage private lawyers to represent individuals before the CCB in a timely manner, given the brief timelines, and so provides lawyers with an assurance that, should an applicant fail the financial test and the lawyer's best efforts to obtain a private retainer or payment agreement meet with failure, the lawyer's work will not go uncompensated.

In the criminal law courts, legal aid certificate coverage is available for criminal charges that mentally ill accused must face as well as for specific issues relating to the tests of fitness to stand trial and for hearings before the Ontario Review Board (ORB). LAO provides criminal law services to mentally ill criminally accused not only when the mental health of the accused is the legal issue, but also in an indirect way, given that a disproportionately large number of people involved with the criminal justice system are known to have mental health issues, whether or not they have been identified as such. The *Legal Aid Services Act* permits area directors to select counsel for accused persons who are unable to do so themselves. This allows area directors to select experienced lawyers for these very vulnerable clients. LAO puts a focus on the client's right to choose their own lawyer and only appoints counsel at the client's request or where the client is unable to choose.

LAO duty counsel provide specialized service in the full-time Mental Heath Court (Ontario's first) at Old City Hall Courthouse in Toronto, as well as in other mental health courts that have been subsequently established around the province, such as Brampton, Ottawa, Newmarket and Barrie.

In Ontario's psychiatric hospitals, legal aid applications for ORB hearings may be taken by a patient advocate or by a legal aid duty counsel. LAO's policy is to apply the financial eligibility guidelines liberally to applicants involved in the ORB hearing process. In particular, persons in custody with modest incomes of $600 per month or less and no significant build-up of assets ($3,000 or less) are issued free certificates for these matters.

The legal clinic system also assists many clients who have mental health issues in the course of providing legal advice and representation to persons whose legal problems do not fall into areas covered by the certificate and duty counsel programs. General service clinics assist clients with housing, income security with a significant focus on disability benefits for clients with both physical and mental health issues, human rights and other issues. Some clinics are "specialty clinics" that provide targeted services in specific legal areas or to specific groups such as youth and seniors. Two specialty clinics that have developed particular expertise in issues related to mental health are the Advocacy Centre for the Elderly (ACE) and the ARCH Disability Law Centre.

LAO is serious about its commitment to providing quality legal services to all of its clients. As part of a larger initiative to establish minimum standards for all certificate and duty counsel lawyers providing services to legal aid clients, LAO has developed more stringent standards to address the issue of providing quality legal assistance to persons appearing before the CCB.

In 2006, LAO established Consent and Capacity Panel Standards, which are mandatory for all certificate lawyers representing legal aid clients before the CCB. The standards require applicants to the CCB panel to meet minimum standards in relation to training and related experience before they may be authorized to accept legal aid certificates for CCB matters. Panel lawyers are also required to comply with LAO's expectations for panel members as set out in the "LAO Expectations for Consent and Capacity Panel Members" document.

In 2007, sub-panel standards for advice lawyers, including mental health advice lawyers, were incorporated into LAO's existing panel standards for duty counsel. The mental health advice lawyer standards require the lawyer to have demonstrated familiarity with the relevant mental health legislation to the satisfaction of the legal aid area director, and to shadow an experienced member of the mental health advice lawyer sub-panel during a probationary period.

As part of its quality standards initiative, LAO endeavours to make continuing legal education and other practice supports accessible to its panel members. Some of the LAO training supports which are of particular relevance to counsel representing a client with mental health issues include:

- A number of memoranda of law prepared by research lawyers at LAO LAW, LAO's in-house legal research department. Topics include "Dispositions – Not Criminally Responsible by Reason of Mental Disorder;" "Dispositions – Unfitness to Stand Trial;" "The *Youth Criminal Justice Act* and Mental Disorder;" "Involuntary Admission;" "Consent to Treatment;" "Financial Capacity Pursuant to the Mental Health Act and the Substitute Decisions Act;" "Capacity and Admission to Care Facilities." Issue-specific research on mental health law topics is also available to panel lawyers.
- Text of decisions of the CCB, as gathered by LAO LAW and made available to panel lawyers on their website.
- DVD training seminars on "Defending the Mentally Ill in Criminal Court;" "Consent and Capacity Two Day Seminar: Nuts and Bolts of Consent and Capacity Law; Appearances Before the Consent and Capacity Board;" and "Designated Representatives."
- Practical Tips documents, compiled by LAO with the assistance of experts in the field: "Representing Minors & Persons with Mental Health Disorders or Disability Before the IRB;" "Helpful Tips for Lawyers Representing Clients Before the CCB."

In the year to come, LAO plans to develop training supports for practitioners who are representing clients at ORB hearings, as a need for training in this area has been identified.

LAO regularly receives input from various expert sources, including the members of its mental health law advisory committee, on issues which are affecting or may potentially affect the provision of legal aid services to clients with mental health issues.

LAO has become a recognized world leader in providing access to justice for persons with mental health issues. Legal aid plans from other jurisdictions have consulted with LAO on how to improve their own mental health law coverage.

At this stage in its evolution as a client-focused organization, LAO takes pride in the contributions it makes on a daily basis to improving access to justice for the mentally ill in Ontario. LAO is also committed to strengthening and improving the services it offers in this area.

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[1] 1998, S.O. 1998, c.26.

[2] R.S.O. 1990, c. M.7.

[3] S.O. 1996, c. 2, Sched. A.

CORONER'S INQUESTS: LEARNING FROM THE PAST TO PROTECT THE FUTURE

Kathy M. Kerr[*] and Bonita M.B. Porter[**]

The origin of coroner's inquests in Ontario dates back to eleventh century England. When a body was found, the representative of the Crown was tasked with determining who the deceased was, where, when and how the person died and who was to blame for the death. With the exception of assigning blame, present-day coroners are challenged with answering the same questions as their historical predecessors. Our modern coroners are medically trained physicians who are appointed to the role of coroner to serve the communities in which they live. Death investigation is a provincial jurisdiction and the duties, activities and powers of coroners are defined within the *Coroners Act*.[1]

The *Coroners Act* provides the legislative authority for coroners to conduct death investigations and inquests in Ontario. Inquests are an inquisitorial process designed to focus public attention on the circumstances of a death. An inquest is a dispassionate public examination into the facts of the death. A coroner presides over an inquest and the jury of five laypeople from the public must determine the verdict. On the verdict, the jury is tasked with answering the five questions: who was the deceased; when did they die; where did they die; how did they die (i.e. the medical cause of death); and the manner of death. For the manner of death, the jury must select from: natural, accident, suicide, homicide or undetermined.

Depending on the circumstances of the death, an inquest may be either mandatory or discretionary. Mandatory inquests are held into deaths arising from accidents in the course of employment at construction, mining, pit or quarry sites, and deaths occurring while being detained or in custody. Recent amendments to the *Coroners Act* now require that inquests be conducted into the deaths of children who die under very specific conditions involving court directed supervision. All other inquests are considered discretionary and may be conducted in accordance with section 20 of the *Coroners Act*.

There are several factors that a coroner takes into account when deciding whether to hold a discretionary inquest. The coroner must consider whether the answers to the five questions – who, when, where, how and by what means – are known. The coroner may also determine whether or not it is desirable for the public to have an open and full hearing of the circumstances of the death.

In addition to determining the verdict, an inquest jury may also provide recommendations towards preventing deaths in similar circumstances. This preventative function is a very important aspect of inquests and it provides a public voice to encouraging changes that contribute to a safer province.

Recommendations from coroner's inquests are taken very seriously and have resulted in changes to legislation, policy, procedures and public attitude. Although organizations and agencies are under no legal obligation to respond to, or implement recommendations, approximately 80% of all organizations asked to respond to recommendations, do so. Of those organizations and agencies responding, approximately 70% of the responses indicate that assigned recommendations were implemented in some manner.[2]

Recommendations have been used as a catalyst for change within many sectors of our society. One area where inquest recommendations have had a significant impact is within the mental health sector where legislation, policy, procedures and public attitude have been reshaped as a result of the public voice expressed through inquest juries.

The Impact of Inquests on the Mental Health System

The interests of psychiatric consumers and survivors have been well represented in coroner's inquests through the active participation of organizations and agencies mandated to protect the interests of this vulnerable population, as well as family members of consumers who are the subject of inquests. These organizations, agencies and individuals play an important role in ensuring that relevant issues and concerns are explored during an inquest with the ultimate goal being the prevention of similar deaths and safer communities for all.

In 1997, 2 ½ year old Zachary Antidormi was stabbed to death by a 58 year-old neighbour who was acting under the influence of a mental illness. The 1999 inquest into Zachary's death was a comprehensive and thorough investigation of mental health legislation, services and policy. The inquest examined the legal framework in which mental health care is provided and the diagnosis, management and assessment of dangerousness in major mental illnesses. The inquest jury made 60 recommendations addressing such diverse areas as police policy for dealing with the mentally ill, the provision of services and support to frontline police interacting with emotionally distressed persons, amendments to the *Mental Health Act*[3] and *Health Care Consent Act*,[4] the provision of funding for public education campaigns and research projects and guidelines for health care and judicial professionals interacting with mental health clients.

The 2004 inquest into the death of Mark Wiens also resulted in recommendations to amend the *Mental Health Act* and the *Health Care Consent Act*. The jury heard how the existing legislation was open to subjective interpretation and was difficult to understand which resulted in provisions of the Acts not being effectively utilized. The jury also recommended that policies relating to "level of responsibility," unauthorized leave and use of restraints, be revised.[5]

One of the common themes of inquests touching on the deaths of psychiatric consumers and survivors is communication: how do frontline service providers, including police and doctors, interact and communicate with psychiatric consumers; what information is shared between frontline organizations and individuals and clients and their families; what general information is disseminated to the public and how can the lines of communications be improved in order to prevent situations from ending in tragic results?

In the inquests into the deaths of Denis Blais (2005)[6] and Hugo Manzano (2000),[7] recommendations addressed the issue of family involvement in the treatment and management of mentally ill relatives, including a review of legislation pertaining to the collection and disclosure of information. Similar communication issues were explored in the Wiens inquest. Other recommendations addressed the development of educational brochures for clients and family members, guidelines for the sharing of progress reports and discharge plans, enhanced training for peace officers and revised policies and procedures for medication distribution within psychiatric facilities.

The theme of information sharing was expressed through the recommendations from inquests into the deaths of Kerri Nicole Cuddy (2004), John Bolger (2005) and Otto Vass (2006). It was recommended by the jury in the Cuddy inquest that the communication process between frontline workers, psychiatric staff and medical care providers be reviewed with a view to increase the flow of information between parties. The jury felt that "a heightened and more clearly directed flow of written communication between designated caregivers and professionals involved would benefit patients."[8]

The jury in the Bolger inquest recommended the creation of a multi-disciplinary task force with representation from the various stakeholders - including consumers of mental health services - to develop comprehensive guidelines that would "protect a patient's dignity and allow for clinical decision-making while ensuring that appropriate safeguards are taken to maximize the patient's safety."[9] The jury in the 2006 Vass inquest had a similar recommendation to "establish an enduring structure for dialogue to address the intersection of policing and issues that arise in the mental health sector."[10]

Issues of relevance to the mental health community have been explored to varying degrees in several inquests over the years. With the goal of preventing future similar deaths, inquest juries have made recommendations pertaining to the safety of psychiatric consumers within the correctional system. These recommendations have covered the diverse areas of training and education for staff, physical construction of facilities, policies and procedures on information sharing and monitoring and the availability of psychiatric and medical resources. More specifically, inquests have explored the unique concerns of women, aboriginals and young people with mental health issues within the correctional environment in Ontario.

Families of psychiatric consumers and the advocacy groups representing the interests of this community, have played an integral role in the inquest process by expressing the challenges and concerns experienced within the mental health system. Inquest juries have listened to these concerns and have responded accordingly by suggesting recommendations to improve the quality of life for not only the psychiatric consumers, but also their families and the community at large. By learning from the past, coroner's inquests are helping to protect the future for all.

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1 R.S.O. 1990, c. C.37.

2 Office of the Chief Coroner, 2004 Report on Inquests. www.mcscs.jus.gov.on.ca/english/pub_safety/office_coroner/about_coroner.html

3 R.S.O. 1990, c. M.7.

4 S.O. 1996, c. 2, Sched. A.

5 Office of the Chief Coroner, Inquest into the death of Mark Wiens, 2004. Verdict and recommendations. www.mcscs.jus.gov.on.ca/english/pub_safety/office_coroner/verdicts_and_recs.html.

6 Office of the Chief Coroner, Inquest into the death of Denis Blais, 2005. Verdict and recommendations. www.mcscs.jus.gov.on.ca/english/pub_safety/office_coroner/verdicts_and_recs.html.

7 Office of the Chief Coroner, Inquest into the death of Hugo Manzano. Verdict and recommendations. www.mcscs.jus.gov.on.ca/english/pub_safety/office_coroner/verdicts_and_recs.html.

8 Recommendation 2, Office of the Chief Coroner, Inquest into the death of Kerri Nicole Cuddy, 2004. Verdict and recommendations. www.mcscs.jus.gov.on.ca/english/pub_safety/office_coroner/verdicts_and_recs.html.

9 Recommendation 1, Office of the Chief Coroner, Inquest into the death of John Bolger, 2005. Verdict and recommendations. www.mcscs.jus.gov.on.ca/english/pub_safety/office_coroner/verdicts_and_recs.html.

10 Recommendation 11, Office of the Chief Coroner, Inquest into the death of Otto Vass, 2006. Verdict and recommendations. www.mcscs.jus.gov.on.ca/english/pub_safety/office_coroner/verdicts_and_recs.html.

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DYING FOR CHANGE: MANDATORY INQUESTS

Suzan E. Fraser[*]

A wise and critical woman recently and wryly noted that one of the major legal victories of the psychiatric community is about death. She was referring to the decision of the Human Rights Tribunal of Ontario (the Tribunal) in May, 2006[1] which held that the *Coroners Act*[2] discriminates by failing to make mandatory inquests into the deaths of people who die in the custody of psychiatric facilities. It was a long, hard victory fought by families and the community. Sadly, on appeal by the Government, the Divisional Court reversed the decision of the tribunal.[3] The parties hope to appeal the decision further but require permission of the court to do so. It is worth asking, however, since the fight is about what happens in death, rather than in life, why bother?

The late Melba Braithwaite, beloved mother to Renata Braithwaite, died on April 9, 2001 at the age of 53 after collapsing in the shower while involuntarily detained at the Centre for Addiction and Mental Health. Her cause of death is noted to be hypertensive cardiovascular disease but questions remain about her death. At the hearing before the Tribunal, Renata gave evidence that shortly after her mother's death, Renata received an anonymous telephone call and the Psychiatric Patient Advocate Office received information from an unidentified staff member calling into question the emergency response by staff and staff ability to respond in a medical emergency. Renata, who was her mother's substitute decision-maker, learned that while in hospital, her mother received a medication to which Renata had not consented. Despite the fact that the coroner's office was statutorily mandated to investigate Melba's death and despite the fact that Melba had been prescribed psychotropic medication, it appeared that no toxicology screen was ever completed. Renata fought unsuccessfully to have an inquest into her mother's death. On January 14, 2003, after the Regional Coroner and the Chief Coroner had refused her request for an inquest, she complained to the Ontario Human Rights Commission.

The late Thomas Illingworth was a letter-carrier who died on June 8, 1995 in the Humber River Regional Hospital at the age of 50. His cause of death is classified as undetermined. What is known is that he suffered from a bi-polar disorder and without his knowledge became involuntarily detained at the Humber River Regional Hospital. He was not seen by a rights advisor. He died in physical restraints 10 hours after a physical confrontation with staff when he attempted to leave the hospital. He was also injected with "chemical restraints." His younger brother, Robert Illingworth, survived him and fought to get answers about the circumstances in which his brother died through the calling of an inquest. On August 7, 2003, after exhausting all efforts to have a coroner's inquest called, he commenced a human rights complaint. This complaint, together with Renata's complaint, was referred to the Tribunal on December 7, 2004. Mr. Illingworth wrote eloquently about his experiences with the coronial system in the 20th Anniversary Special Report of the Psychiatric Patient Advocate Office. Sadly, the struggle for equality continues to this day.

Had Melba or Thomas died in a police holding cell, in the custody of police in a police car, in a halfway house or in a correctional facility, an inquest would be mandatory. Dying behind the locked doors of a psychiatric facility doesn't get you an inquest, only an investigation. So what is the big deal about an inquest anyway? An inquest is a public proceeding and creates a full public record. Witnesses are called, placed under oath, examined and cross-examined. People connected to the death can apply for standing. If granted, those people or their lawyers can cross-examine witnesses, call their own witnesses and make submissions. The evidence is heard by a jury of five people who must determine who the person was, where, when and how they died. They may also make recommendations to prevent similar deaths in the future. So it is about public safety - our people and our community's safety.

The importance of an inquest was noted by the Law Reform Commission of Ontario in 1971:

> One of the primary assumptions underlying the common law, as well as the moral and social rules and values upon which our civilization is based, is the clear policy relating to the need to preserve and protect human life ... The death of a member of society is a public fact, and the circumstances that surrounded the death, and whether it could have been avoided or prevented through the actions of person or agencies under human control, are matters that are within the legitimate scope of all members of the community... The role of the office of coroner must keep pace with societal changes and, where necessary, must move away from the confines of doctrines that are inconsistent with community needs and expectations in twentieth century Ontario.[4]

While the Report noted that the coroner's inquest serves an important investigative function in determining who the deceased was, where, when, how and by what means she died, it also stated that a coroner's inquest should serve a second major purpose:

> Beyond this bare determination of facts, a coroner's inquest should serve a second major purpose. This is a vehicle through which the public can formally learn of deaths that have occurred or are rumoured to have occurred under circumstances which indicate malfeasance, insufficient safeguards, failure to take precautions, neglect of human life or homicide. ... In addition to providing a means through which the community can initiate corrective measures in some cases, the inquest can also allay suspicions in others by bringing out the truth in lieu of groundless supposition and potentially corrosive conjecture. A modern coroner system should be premised upon an awareness of these aspects of human nature, and should allow the conduct of inquests in response thereto.[5]

The Ontario courts have also recognized the value of public scrutiny in deaths occurring in institutions normally shielded from public view in *Stanford v. Harris*, a case about standing at coroners' inquests:

> One of the functions of an inquest into a death in a prison or other institution not ordinarily open to public view is to provide the degree of public scrutiny necessary to ensure that it cannot be said, once the inquest is over, that there has been a whitewash or a coverup. There is no better antidote to ill-founded or mischievous allegations and suspicions than full and open scrutiny.[6]

At the risk of oversimplifying for this brief paper, the Divisional Court found that the distinction in the *Coroners Act* is not discriminatory. It noted that conditions in jails are more dangerous. It also justified the differential treatment based on the purpose of the detention in that it was "therapeutic" rather than punitive. This approach fails to appreciate the real experiences of the person held down by security, behind a locked or double-locked door, injected with "chemical restraint," placed in physical restraints and left in restraints at the discretion of nurses.

We need more ways to open the doors to psychiatric facilities in order to protect our citizens. Environments that are open and respect rights are safe environments. The more scrutiny into what happens behind the walls of a psychiatric hospital, the safer our community will be. An inquest is a way of opening those doors.

Ultimately, this quest for mandatory inquests is about whether people who are detained by the state in a psychiatric facility by virtue of mental disability have the same rights as those detained for other reasons. It is about whether when they die while detained in a mental health facility, their death receives the same level of public scrutiny as people detained in a penal facility. It is about whether they, their families and their community should have the benefit of an inquest as they would have, had they died in jail or other penal facility. The dignity, safety and equality of vulnerable psychiatric in-patients require an equal process by which the coroners' system gives equal value to their lives through equal examinations of their deaths.

[*] Suzan E. Fraser is a Barrister and Solicitor in Toronto.

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[1] *Braithwaite v. Chief Coroner* (2006), 56 C.H.R.R. 171 (H.R.T.O.),

[2] R.S.O. 1990, c. C.37.

[3] Reversed under the name *Ontario (A.G.) v. Ontario (Human Rights Commission)*, [2007] O.J. No. 4978 (Div. Ct.).

[4] Ontario Law Reform Commission, Report on the Coroner System in Ontario (1971) (hereinafter "Report on Coroners, 1971"), at page 25.

[5] *Ibid.*

[6] [1989] O.J. No. 1068 (Div. Ct.) at 19 [Q.L. Version].

ANNIE'S STORY: A CANARY IN THE MINE OF MEDICAL ETHICS

Barb Farlow*

Our daughter Annie was diagnosed before birth to have a genetic condition related to multiple serious anomalies. Traditionally, it was considered to be in the best interest for infants born with the condition to be managed in a supportive or palliative manner.

After doing extensive research, we realized that some children with Annie's condition benefit from diagnosis and surgery or other treatment and live happily for many years, despite their limitations. We decided that we wanted to give her a chance. We then set out to discover how the applicable policies at the Hospital would guide Annie's medical care and allow for our input and choices.

We were soundly assured by the staff of three departments at the Children's Hospital that our daughter would receive the same medical care as any child. Specifically, Annie would receive a diagnosis and, in partnership with the physicians, we would make a decision regarding the course of treatment that would be in her best interest.

It should have been very simple yet when Annie died at the age of 80 days we were left with many unanswered questions.

Almost two years later, we were in possession of a Paediatric Death Review Committee report from the Coroner's Office which stated, "the events of the final 24 hours and the initiation of palliative care together with writing of a DNR order,...... do not represent appropriate forms of care" and "...life prolonging treatment may impose a greater burden and greater distress on the child than its withholding. However in the case of Annie Farlow there is no evidence that she was in such distress and it was by no means certain that she would have to undergo prolonged burdensome interventions such as prolonged ventilation or distressful surgery."

A specific cause of death could not be determined.

Annie had died within 24 hours of arrival at the Hospital under circumstances which the Chief Coroner has described as tragic. When she suffered a respiratory crash, the records reveal that no call was made to the intensive care unit for over an hour. A Do Not Resuscitate (DNR) order had been issued without informed consent and there were multiple, serious violations in nursing standards related to the administration of medication.

We had been informed that our daughter needed a surgery she would not likely survive, but later we discovered that the appropriate diagnostic testing required to make this determination had not been done. Several possibilities could have existed, and the required treatment for some of them was relatively minor.

How could this have happened? The Hospital had not been busy. We never left Annie's side. We were respectful of, and always showed appreciation to all of the staff. We came to realize that many clinicians would have been aware that Annie's medical issues were not being managed in the standard way, yet none of them intervened. The disturbing lack of ethics was therefore systemic.

The only supportable conclusion of this tragedy was that Annie must have received different treatment because her genetic condition was associated with cognitive and physical disabilities. It appeared that a quality of life judgement had been made. The Coroner's Office was unable to determine the source of Annie's respiratory problems.

It is important to share the anguish of a family in a situation like this. For months, we could barely function as we came to realize the truth about Annie's medical care. The events surrounding her death played over and over in our minds and we could not move past them. In a meeting many months after Annie's death, the Chief of Critical Care asked us why we didn't challenge the physicians when Annie's growing symptoms were ignored. This statement exacerbated our pain and we blamed ourselves for not asking more questions or realizing that something was wrong.

The truth is that my children have lost both their sister and their mother as a result of the manner of Annie's death. The mother who once knew every minute detail of their special lives can think of little else besides Annie's situation. We had been prepared for our daughter's death, given the statistics related to her condition, but we could not accept or disregard the circumstances of her death.

Our fundamental parental rights to be informed and to be involved in decision-making had been violated without cause. Without benefit of a committee, judge, or jury, we had apparently been declared parents who were unwilling to make the decisions that the system wanted us to make. Those who deemed themselves better able to decide what was in best interest for Annie had systemically ignored critical carbon dioxide levels and as a result, Annie died a slow and tragic respiratory death. Had we known that a diagnosis for life-saving treatment had been denied and that our daughter's death was imminent, we would have ensured that her death was peaceful and dignified.

I researched the medical, legal and ethical elements of the situation exhaustively. I contacted ethicists, disability leaders, politicians, health policy analysts and hospital administrators in an attempt to gain an understanding of what had occurred. My husband and I knew that we could find peace only when we had reached an understanding and discovered a way to affect change in order to prevent a reoccurrence of our tragedy.

We did not want Annie's life to leave us with anger or bitterness and it seemed that working *with* the system would be the best way to achieve our goals of improving ethics and family-centred care at the Hospital. We were certain that our sincere, conciliatory and collaborative approach would lead to an effective resolution.

After several Hospital meetings failed to provide the answers or understanding we sought, we notified the Chair of the Board of Trustees and an immediate internal review was ordered. Upon its completion, a carefully worded apology was issued: "Sometimes, when we care for children such as Annie, who have very complex care needs, and there are many individuals involved and consulted, communication does not occur in as clear and consistent a fashion as we would wish. For that, we are very sorry."

While the admission and apology were significant and appreciated, we did not believe that effective plans were put in place to improve ethics and family-centred care. We suggested that a parents' advisory council could be formed for the intensive care unit. We proposed that education should be provided to physicians regarding the quality and value of the lives of children with disabilities according to their parents. There was no interest in these, or similar suggestions.

Along the way, we have discovered that there are no special mechanisms in the system which serves to defend and protect our vulnerable populations.

Medical school curriculum does not ensure the provision of education related to the rights of patients or the value of challenging lives. There is no independent government body to receive a complaint when medical care is questionable. The Ontario Ombudsman has no jurisdiction over hospitals. There are very few cases of discipline imposed by the College of Physicians and Surgeons of Ontario which relate to the provision of medical care for society's vulnerable members. There is no effective civil law protection because the value of such lives is so much less than the legal costs involved.

Hospital policies are written to reflect a patient's civil and human rights and are carefully approved at every level of the organization. It has been our observation that these policies are not implemented through the promotion of ethics and there is no accountability to them.

The primary input involved in the daily operation of hospitals appears to relate to Ministry of Health and Long-Term Care objectives and performance indicators which are directly tied to funding. We question how such standards are developed and whether they involve input from representatives from the vulnerable communities. Are unilateral treatment decisions based on quality of life valuations rather than medical outcome being made? If this is the case, then such decisions would be a contradiction of the *Universal Declaration of Human Rights*.[1] Is this acceptable to society?

It is with these questions and concerns that we acquired support from most of the major disability organizations in Canada for our quest to obtain a coroner's inquest. Although our focus is related to the issues surrounding medical treatment for infants with predicted disabilities, we realize that the core of our concerns is shared by many.

It has been said by many great leaders in history that *a society can be judged by how it treats its weakest members*. When an innocent child suffers unnecessarily and is provided with medical care that is inconsistent with hospital policies, professional codes of ethics, health care laws and basic human rights, serious questions must be asked and answered.

Our tragic experience reveals that it is time for Ontario to undertake a comprehensive review of its medical system with regard to the provision of medical care for the vulnerable. If we are to remain a compassionate and humane society, this review is vital.

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[1] Adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948.

ADVOCATING FOR AN INQUEST – ONE FAMILY'S JOURNEY

Paul and Maryann Murray *

Dr. Margaret Chan, Director-General of the World Health Organization has stated: "*Our greatest concern must always rest with disadvantaged and vulnerable groups*."[1] Our daughter, Martha, was a member of such a group. Martha suffered from both physical and mental illnesses, yet the mental health diagnosis may have created a bias, prompting physicians to repeatedly dismiss physical symptoms and abnormal tests with tragic results. That this took place for years indicates the systemic nature of the issue. The co-ordination between mental and physical health care among this vulnerable group should be thoroughly and publicly examined at a full public inquest in order to save the lives of others.

Martha was a 22-year-old nursing student who lived at home and had complex health issues, including hypokalemia (chronic low potassium) and mood swings diagnosed as bipolar disorder. Yet despite being a high-risk patient, Martha was unable to convince local physicians to refer her to a mood disorders clinic for treatment. In the summer of 2002, a psychiatrist, along with Martha's family physician, began prescribing lithium to treat her bipolar disorder. We later learned that a specialist's warning, contained in Martha's medical file, advised against prescribing lithium (lithium combined with low potassium can cause cardiac arrest). In September 2002, the dosage of lithium was increased. Thirteen days later, without warning, Martha suffered a fatal cardiac arrest. Our quest for answers and accountability has been hampered by those in authority for the last five years and is still ongoing.

The following chronicles our continuing efforts to open an inquiry into Martha's death.

September 2002

We immediately related our concerns of Martha's medical care to local authorities, yet medical files were not examined prior to autopsy and months later, when autopsy and toxicological results were complete and provided no cause of death, Martha's death was simply classified as "natural."[2] This was the first we learned that in Ontario, coroners may identify a death caused by medical treatment or iatrogenic error as "natural." To support this decision, a coroner provided a copy of an internal memo titled *By What Means*, which defines a natural death as a "*death due to a disease, or a complication of a disease or its treatment.*"[3] We believe these definitions, which are not included in the *Coroners Act*,[4] have led to systematic cover-ups of deadly medical errors, preventing administrative and legislative action to help avoid future similar errors and deaths.

February 2003

We began lobbying for an inquest in February of 2003. Dr. Jim Young (then the Chief Coroner of Ontario) refused our request, but asked Dr. Jim Cairns and the Paediatric Death Review Committee (PDRC) to review this fatality. Since Martha's health issues and treatment began in her paediatric years, the choice seemed reasonable. Only recently did we learn that disgraced pathologist Dr. Charles Smith was a member of the PDRC in 2003.[5]

In order to examine Martha's medical files, Coroners Warrants were faxed to several locations requesting her complete medical files. In November 2003, the PDRC completed their review and released a report on Martha's death.[6] They noted the specialist's warning in Martha's file advising against prescribing lithium due to electrolyte concerns and pointed out that prescribing lithium under these circumstances "would put her at risk for a cardiac event." However, the PDRC failed to determine if lithium was the cause of Martha's fatal cardiac arrhythmia and failed to answer "how" or "by what means" Martha died. As questions remained and there were no recommendations aimed at preventing similar deaths, we continued to lobby for an inquest.

Autumn 2004

The Regional Coroner again refused our request for inquest in September 2004 and wrote, "I would question the value of this type of public inquisition into potentially very private and personal family matters."[7] Rather than accept that examination of mental health treatment could become a public inquisition of the victim, we increased our efforts to obtain an inquest. We created a website at www.marthamurray.ca. We collaborated with CBC Radio in their Faint Warnings series, which detailed the lack of reporting of adverse drug reactions in Canada. We spoke to reporters who covered our efforts, and met with Ontario's Minister of Health and Long-Term Care. We gained the support of the Vice Chair of the Office for Victim's of Crime,[8] as well as the Federated Women's Institute of Ontario.

We visited the Legislative Assembly of Ontario twice[9] where the issue of Martha's death was raised. The first time occurred on November 29, 2004 in Question Period when Member of Provincial Parliament Shelley Martel asked Monte Kwinter, Minister of Community Safety and

Correctional Services, to order an inquest. Although section 22 of the *Coroners Act* gives the Minister the power to order an inquest, Mr. Kwinter refused stating: "The Chief Coroner's office has to stay above political interference." At the time, we were unaware that Dr. Jim Young was simultaneously the Chief Coroner, as well as the Assistant Deputy Minister for the Ministry of Community Safety and Correctional Services – meaning he was responsible for overseeing the Chief Coroner. In retrospect, it is not surprising that Dr. Young would not advise the government to override his own decision to decline an inquest.

February to April 2005

Dr. Barry McLellan, Ontario's new Chief Coroner, also declined our request for an inquest in February 2005 stating: "I am not convinced, given the issues identified through my review, that the best way to advance public safety is by a public review of the circumstances surrounding Martha's death." [10] Instead, Dr. McLellan created a new Patient Safety Review Committee and asked the chair of this committee to review Martha's death and issue recommendations. This review resulted in the means of Martha's death being changed from "natural" to "undetermined."[11] However, there were no plans to change the determination of a "natural" death for others in Ontario.[12]

This review resulted in five provincial recommendations, none of which involved medical treatment of patients with mental illness in Ontario. Instead, recommendations focused on the: education of physicians regarding identifying a lead physician; risk of lithium therapy associated with hypokalemia; education of patients on risks associated with lithium; development of electronic medical records; and reporting of deaths due to adverse drug reactions to Health Canada.[13] Of these recommendations, only the Coroners' Office complied and agreed to begin reporting fatalities to Health Canada where adverse drug reactions were suspected.

On April 5, 2005, Ms. Martel again raised the issue of Martha's death in The Legislative Assembly during Question Period and requested a government committee examine the findings of deaths related to natural causes as described by coroners and whether these deaths might not be natural at all. George Smitherman, Minister of Health and Long-Term Care, replied on the record that he would investigate and respond, but to date there has been neither a response nor an investigation.

Also in April 2005, after almost a year of requesting access to Martha's heart, the Chief Coroner confirmed that Martha's heart was destroyed upon completion of the initial autopsy.[14] Although subsequent expert review requested a reexamination of Martha's heart,[15] the destruction of evidence during the initial death investigation prevented this from happening.

April 2006: Missing Evidence

In April 2006, we discovered cardiac reports and abnormal tests omitted from files obtained under four Coroners Warrants. We provided these records to the Chief Coroner who reopened his investigation. A subsequent review of 17 electrocardiograms confirmed that all were abnormal and indicated an underlying heart defect.[16] We had many unanswered questions since physicians who treated Martha had for years dismissed so many abnormal cardiac tests and several health care practitioners has failed to produce files that were the subject of Coroners Warrants. The fact that the College of Physicians and Surgeons of Ontario was aware of such omissions also raises concerns.

2008

It is now 2008 and the Chief Coroner's Office claims to be continuing the examination of Martha's death, as well as the failure to comply with Coroner's Warrants. As these issues have been unresolved for more than five years, it is time for a public examination of Martha's death. Only a public inquest into Martha's death would examine the following issues:

- How and why Martha was prescribed a drug that was known to be contraindicated and potentially deadly for her condition;
- Whether abnormal cardiac tests were ignored due to systemic issues surrounding treatment of psychiatric patients;
- The "take care of yourself approach" to psychiatry referred to by Martha's physicians and an independent opinion accepted by the College of Physicians and Surgeons;[17]
- Provincial funding initiatives aimed at reducing specialist referrals;[18]
- The practice of faxing of Coroners Warrants, and the risk of evidence omission;
- Authorization of the destruction of evidence during a death investigation;
- Whether a death by medical treatment in Ontario should be identified as "natural;" and
- Establishing systems for reporting and dealing with health-care harm on a provincial level.

To quote the World Alliance for Patient Safety: "We cannot let the current culture of error and denial continue. We call for honesty, openness and transparency. We will make the reduction of health-care errors a basic human right that protects human life around the world."[19] In Ontario, we must demand transparency and accountability in our Chief Coroner's Office. Public inquests into deaths like Martha's provide the opportunity to examine current practices and facilitate changes that will improve patient safety and save lives.

[*] Paul and Maryann Murray are lifelong Ontario residents and parents of five, who have become patient safety advocates following the death of their daughter Martha.

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9 Full text available under More Information and Questions in the Ontario Legislature at www.marthamurray.ca.

10 Letter from Dr. Barry McLellan, Chief Coroner for Ontario, to Paul and Maryann Murray, February 4, 2005.

11 Coroner's Investigation Summary signed by Dr. Barry McLellan, Chief Coroner for Ontario, February 4, 2005.

12 Letter from Dr. Bonita Porter to Maryann Murray, February 9, 2005.

13 *Supra* note 12.

14 Letter from Dr. Barry McLellan to Paul and Maryann Murray dated April 6, 2005.

15 Report from Dr. J. Kirsh, HSC/University of Toronto Faculty of Medicine, June 15, 2006.

16 *Ibid.*, Nov 20, 2006.

17 Report to Dr. R. Gerace from anonymous reviewer on care provided to Martha Murray, September 13, 2005.

18 Letter from Ministry of Health and Long-Term Care, Alternative Payment Programs Branch signed by Marsha Barnes, Director, May 29, 2003.

19 London Declaration, Patients for Patient Safety, WHO World Alliance for Patient Safety, January 17, 2006.

HUMAN RIGHTS TRIBUNAL OF ONTARIO: ENSURING ACCESSIBILITY

Michael Gottheil[*†]

Introduction

On June 30, 2008, *Bill 107, An Act to Amend the Human Rights Code,*[1] will come into effect. Bill 107 significantly reforms the system of resolving human rights complaints by allowing individuals who believe they have been discriminated against to file an Application directly with the Human Rights Tribunal of Ontario, where the parties will have timely access to effective mediation and expert adjudication.

This paper, prepared for the Psychiatric Patient Advocate Office's 25th Anniversary Special Report, will highlight how, *at every stage*, the Tribunal is working to design a process that advances the goals of the legislation, that ensures access to justice and that can effectively and fairly address a wide range of human rights claims. To meet these goals, the Tribunal will develop rules, processes and procedures that will allow it to be flexible and able to address the individual case before it.

The Tribunal is committed to on-going consultation with the communities who will access the system. We encourage you to visit our web site, www.hrto.ca, to find more information about the Tribunal, and to keep track of further details as they develop. We welcome your questions and comments.

The Mandate of the Tribunal

Under the amended *Human Rights Code,*[2] both the Ontario Human Rights Commission and the Human Rights Tribunal will have new mandates. As well the legislation establishes a fully-funded arm's length agency that will provide no-cost legal services to persons who wish to pursue a human rights claim under the amended process.

As of June 30, 2008 the Tribunal[3] will take responsibility for the entire complaint resolution process from the point at which a completed application is filed. The Tribunal will no longer receive cases that have already been through intake, investigation, mediation, conciliation and a fact-finding process at the Commission.

The Tribunal must develop a process that includes:

- early determinations on jurisdiction and deferral
- production and disclosure opportunities to ensure that parties are able to obtain the evidence needed to litigate on the true merits
- effective mediation
- expert adjudication.

Ultimately, the Tribunal must develop procedures and practices that offer "the best opportunity for a fair, just and expeditious resolution of the merits of the applications."[4]

Context

According to Ontario Human's Rights Commission's 2006 - 2007 Annual Report,[5] the three most cited grounds of discrimination are disability, race and colour and ethnic origin: of new complaints 56.31% were based on disability grounds, 35.82% based on race and colour and 14.16% on ethnic origin.

The Tribunal knows that it will be dealing with many different people. The people who wish to access the system will have varying degrees of ability, may have mental illness, may not be familiar with judicial processes and may distrust people and institutions of authority. We strive to make the system accessible to all persons at every step.

Core Values of the Tribunal

The Tribunal's process will give expression to the following key values:

- *Accessibility*: both physically and functionally.
  - *Physically*: everything from the hearing rooms to the publications and information will be designed in a way which does not create barriers to people who seek to participate effectively in the Tribunal's processes.
  - *Functionally*: all people, whether involved as claimants, respondents or other interests, will be able to feel that the process is understandable, fair and relevant to their own experiences, whether or not they are represented by a lawyer.
- *Fairness*: the process will ensure that decisions are based on the facts, the law and the merits of the case.
- *Transparency*: Tribunal procedures will be clearly established and decisions will be made in an open way, with substantive reasons that are clear, concise and understandable.
- *Timeliness*: resolutions will be reached and decisions made in a timely way, so that delays do not frustrate the objects of the Code – to prevent discrimination and if a violation is found, to provide effective, meaningful remedies.
- *Opportunity to be heard*: an application that is within the jurisdiction of the Tribunal will not be finally determined without giving the parties an opportunity to make oral submissions.

Legal Assistance

The new Human Rights Legal Support Centre[6] will open its doors on June 30, 2008 and is mandated to provide "support services" throughout the province, including "advice and assistance, legal or otherwise" to individuals "in respect of infringements of rights" under the *Code*.

The Centre is required by the legislation to provide legal services in relation to:

- completion and filing of applications to the Tribunal;
- proceedings before the Tribunal;
- judicial review applications arising from Tribunal proceedings;
- stated-case proceedings arising from Tribunal proceedings; and
- enforcement of Tribunal orders.

It is expected that the Centre will give legal advice on the merits of a possible claim, assist in identifying supporting evidence, and assist in completion of an application to the Tribunal. The Centre may establish criteria to govern its service delivery, but the Government has indicated that the Centre would be mandated to provide no-cost legal services across the province:

- at the application stage, to would-be claimants who want assistance in completing an application to the Tribunal; and
- at the hearing stage, to those applicants whose claims will be decided after a full hearing on the merits.

An applicant is not required to use the Centre's services and can file an application with the Tribunal without getting assistance from the Centre. The Tribunal does not assume that all people will have legal representation.

The Tribunal Process

The Tribunal is working to ensure that every party can effectively participate in the resolution of an Application.

To meet this end that Tribunal will produce plain language guides and fact sheets that will help people to frame their claim and to understand and navigate the system. The Tribunal Application Form, which has been developed with a plain language and design consultant and user group feedback, aims to draw out important detailed information at an early stage. The goal is to enable the parties to move promptly to a rights-based mediation, or where appropriate, directly to a determination on the merits.

Integrated mediation is a part of the Tribunal's resolution process. Mediation will be voluntary in all cases and can be requested by the parties. The term "integrated" refers to both the procedural and substantive aspects of the mediation model. Mediation will be conducted by members of the Tribunal who can undertake case management function (for example, order production or fix dates for preliminary arguments) if settlement discussions are unsuccessful. On a substantive level, the integrated mediation model incorporates a number of adjudication values, including the right to be heard by a neutral expert.

As required by legislation, adjudicators have been appointed following a competitive process. The Tribunal adjudicators all have experience, knowledge and training with respect to human rights law and issues. At a hearing, the adjudicator may take an active role in focusing and structuring the proceeding. In each case, an adjudicator will determine, after hearing from the parties, how to conduct the hearing to afford the best opportunity for a fair, just and expeditious resolution of the merits. Parties will not necessarily be given the unlimited right to call whatever evidence they choose, in whatever manner, but they will be given the opportunity to be heard on the hearing process before any limitations are imposed.

Conclusion

The Tribunal is engaged in a significant transformation. In one way, its mandate remains the same: to resolve, through mediation and adjudication, claims filed under Ontario's human rights legislation. However, with the responsibility for the resolution of all individual claims being shifted from the Commission to the Tribunal, the Tribunal must create accessible and fair processes to ensure that individuals are confident in their ability to access and engage in the new system.

The *Code* requires the Tribunal to adopt practices and procedures that will afford the best opportunity for a fair, just and expeditious resolution of the merits. It empowers the Tribunal to adopt practices and procedures that are alternative to traditional adjudicative or adversarial procedures.

In determining the appropriate dispute resolution model, the Tribunal faces the additional challenge of the unknown: how many cases will we actually receive; will the majority of the parties be represented or self-represented (or under-represented); will there be a significant increase in matters that arise outside the Toronto area; will parties choose mediation; will the user community bring early challenges to the Tribunal's new process; will the courts give the Tribunal deference in respect of its process and its substantive decisions?

All of these questions play into the decisions that the Tribunal must make in the coming months before proclamation and the launch of the new system. Over the past 18 months, the Tribunal has studied the best practices in administrative justice and has been guided by extensive community and stakeholder consultations. The consultations will continue and our first years of operation will be an ongoing period of consultation and reassessment.

The greatest challenge perhaps is the need to balance the public interest role that the Tribunal is required to play under the *Code* and the more narrow function of individual dispute resolution. In the end, however, these two mandates are not that divergent. While there is a public interest in eliminating discriminatory policies and barriers, and in promoting equality and *Code* compliance, there is likewise a public interest in ensuring that individuals have timely access to a Tribunal that can resolve human rights claims fairly and expeditiously, through a transparent and understandable process.

[*] Michael Gottheil is the Chair of the Ontario Human Rights Tribunal.

[†] Michael Gottheil acknowledges the research and writing assistance of Kathy Laird, Counsel to the Chair, Human Rights Tribunal of Ontario and Grace Vaccarelli, Policy Advisor, Human Rights Tribunal of Ontario.

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[1] C.30, S.O. 2006.

[2] *Human Rights Code*, R.S.O. 1990, c.H-19, as amended by: 1993, c. 27, Sched.; 1993, c. 35, s. 56; 1994, c. 10, s. 22; 1994, c. 27, s. 65; 1995, c. 4, s. 3; 1997, c. 16, s. 8; 1997, c. 24, s. 212; 1999, c. 6, s. 28; 2001, c. 13, s. 19; 2001, c. 32, s. 27; 2002, c. 18, Sched. C; 2005, c. 5, s. 32; 2005, c. 18, s. 17; 2005, c. 29, s. 1; 2006, c. 19, Sched. B, s. 10; 2006, c. 21, Sched. F, s. 136; 2006, c. 30; 2006, c. 35, Sched. C, ss. 54, 132. ("*Code*").

[3] *Code*, Part IV.

[4] *Code*, s. 40.

[5] Ontario Human Rights Commission, www.ohrc.on.ca/en/resources/annualreports/ar0607.

[6] *Code*, Part IV.I

MAKING MENTAL HEALTH AND ADDICTIONS A PRIORITY – ONTARIO LHINS MOVE FORWARD

Elizabeth Trew[*]

Transforming Ontario's Health Care System

In 2004, Ontario Health Minister George Smitherman created a vision to transform Ontario's health care system:

"To develop a health care system that helps people stay healthy, delivers good care when they need it, and will be there for their children and grandchildren."

The status quo was no longer good enough. To achieve this vision, health care delivery will transform from a service driven, centrally-planned system to an integrated, patient-centred system of care to meet local needs. The first step in achieving this vision was the creation of fourteen Local Health Integration Networks (LHINs) to plan, co-ordinate and fund health care to make it easier for patients to access the care they need. The LHINs are mandated to engage their communities to find out about their need and priorities. The LHINs went to local health service providers, health care consumers and their families to find out their concerns and used what they heard to identify local clinical and operational priorities to develop individual Integrated Health Service Plans (IHSPs) for 2007-2010.

Along with this transformation in health care delivery, the province increased funding for community-based mental health and addictions services for the first time in twelve years. The LHINs could effect real change as they had both the funding and mandate to do so.

The Voice of the Mental Health and Addictions Sector

The major players in the mental health and addictions sector – the Canadian Mental Health Association – Ontario (CMHA-Ontario), the Centre for Addiction and Mental Health (CAMH) and the Ontario Federation of Community Mental Health and Addictions Programs (OFCMHAP) – participated in the transformation agenda from the beginning. Early on, they met to identify key themes to guide the government's agenda so that people living with mental health and addiction issues would benefit. These themes included principles for a transformed health care system and criteria for evaluating the LHINs. In a joint public statement,[1] these organizations indicated their support of the government's goal of providing a continuum of care to people in their communities and the critical role of community-based services for people who need help for mental health and addiction problems. They were pleased that Minister Smitherman was championing the needs of people with mental health and addiction issues.

Community Engagement Activities

In 2006, the LHINs held community engagement sessions to obtain the input of health care providers, consumers and their families, thereby giving the mental health and addiction community an opportunity for their voices to be heard. Across Ontario, several thousand people and organizations provided valuable input to develop specific priorities for action that their LHIN should take.

The LHINs heard that mental health and addictions issues needed to be addressed in their community and must receive more attention with respect to funding and research. They found families struggling to care for loved ones with mental health problems, receiving little guidance, support, relief or respite. They found people living with mental illness facing discrimination, unemployment, poverty, homelessness and social isolation. They found family members giving up jobs to care for a loved one, with the loss of income further adding to their stress.

Mental Heath and Addictions - The Leading Cause of Disability in Canada

More Canadians are disabled by mental illness and addictions than by cancer, heart disease, stroke or accidents.[2]

Mental health and addictions affect how long one lives. Having an addiction increases the likelihood of having other serious health problems – heart disease, stroke, seizures and certain types of cancer – and can shorten one's life. Alcohol use can cause falls, drowning and motor vehicle accidents, often resulting in severe disabilities or death.[3] The death certificate of these victims might indicate a cardiac arrest or motor vehicle fatality but to the families of these victims, alcohol or substance abuse was the real cause of death.

Who Lives With Mental Illness and Addictions?

According to Health Canada, of Canadians 15 years of age or older:

- 1 in 5 will experience a mental illness in their lifetime.[4]
- Between 10% and 20% will have a substance use disorder in their lifetime.[5]
- 1 in 10 will experience mental health issues (major

depression, mania disorder, panic disorder, social phobia and agoraphobia) and/or alcohol or illicit drug dependence in any given year.[6]

- 3% will depend on alcohol and illicit drugs in a given year.[7]
- 5% have the potential to become – or are already – problem gamblers.[8]

Mental illness and addictions often go hand in hand. The likelihood of having one of these disorders and also having the other disorder is very high. About 30% of people diagnosed with a mental illness will also have a substance abuse problem in their lifetime. As well, 37% of people who abuse alcohol also have a mental illness, and 53% who abuse drugs also have a mental illness.[9]

A Focus on Addictions and Mental Health: A Review of the LHINs IHSPs

Major mental health and addictions organizations in Ontario are working with the LHINS to determine the extent of the work of the LHINs that support the needs of people with addiction and mental health problems and their families.

In 2007, Addictions Ontario, CMHA-Ontario, CAMH and OFMHAP collaborated to review IHSPs from all 14 LHINS to assess the extent to which each LHIN addressed addiction and mental health issues and whether their priorities were translated into action plans.

This comprehensive review, "A Focus on Addictions and Mental Health: Review of LHIN Integrated Health Service Plans,"[10] highlights what is working well and what needs to be done to ensure that the LHINS have strong mental health and addiction services and supports.

What They Found

The authors were pleased that every LHIN is addressing addictions and mental health to some extent, although the sector is a priority in only half the LHINs and a sub-priority in another five LHINS. The authors did have some concerns. Access and service gaps were not consistently addressed within all LHINS because they focused on integration. Barriers to accessing services, particularly among marginalized groups were missed. Diversity issues were often not addressed as adequately as the LHINs focused on language barriers, rather than on providing culturally appropriate services. Few LHINs addressed the importance of housing, income, employment and social supports for people with mental health and addictions issues. Furthermore, most LHINS were not able to demonstrate the importance of involving consumers and families in the planning, delivery and evaluation of services.

The report identified fifteen criteria for evaluating the content, development and implementation planning for the IHSPs and ranked each criteria on a four point system, ranging from whether the criteria was mentioned at all to whether it was strongly addressed. The report included a critique of all 14 LHINs so each LHIN could identify best practices in other LHINs and analyze where their own LHIN fell short.

Recommendations

The authors asked the province to consider strengthening the addictions and mental health system as a strategic priority.

They called for each LHIN to maintain a focus on addictions and mental health and for the sector – consumers, families and service providers – to work together.

They called for the LHINs to review the capacity of the existing service system before any integration efforts could be made. Many LHINS are doing just that. You cannot build on a system until you know what is working and what needs to be changed.

Urgent Priorities Funding – Bringing the Mental Health and Addictions Sector Forward

Many of the LHINs have used 2007/08 funding to address local priorities identified by consumers and health service providers. Here are a few of the many projects the LHINS are working on to address integration efforts in their communities:

- Erie St. Clair LHIN provided one-time funding for the Windsor Salvation Army Substance Abuse Treatment Program for Homeless Men, as its funding is in jeopardy due to city budget cutbacks.
- Waterloo Wellington LHIN provided funding to create a residential addiction treatment pilot program as the first step towards the potential creation of an addiction treatment centre for 40 youth.
- Toronto Central LHIN provided funding to develop and implement a centralized access and referral system for 3,800 mental health supportive housing units provided by 32 organizations.

In addition to funding urgent priorities in the mental health and addictions sector, virtually all the LHINS have convened multi-sectoral system planning tables to assist in IHSP implementation efforts, including priorities identified for mental health and addictions. Consumer/survivor and family participation has also been incorporated into these structures through workshops, education sessions and organized working groups across the province. Most LHINs are also making efforts to address identified mental health and addictions issues through their IHSP priorities. Although some LHINs did not make mental health and addictions issues a priority when they wrote their IHSPs in 2006, a year and a half later, every LHIN is working towards integrating and improving services for this often neglected sector of the health care system. Several LHINs are reviewing strategies to address the recommendations outlined in the Reville Report[11] commissioned by the Ministry of Health and Long-Term Care, which outlined integration opportunities for the mental health and addictions sector.

Focus on the Future

The LHINs have made substantial progress during the past year towards integrating and improving services for people in their local communities with mental health and addiction issues. Working collaboratively with major players in the mental health and addictions sector, the LHINs will continue to follow up on this important component of our health care system. For more information about the work of the LHINs in the Mental Health and Addictions sector, visit www.lhins.on.ca.

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MENTAL HEALTH DISCRIMINATION – LIFTING INVISIBLE BARRIERS

Barbara Hall*

According to Health Canada, approximately 20% of Canadians will experience mental illness in their lifetime.[1] Unfortunately, persons with mental illness often still face stigmatization, stereotypical attitudes and discrimination at work, at home, in schools or even getting services.

Under the Ontario *Human Rights Code*[2] (the "*Code*") everyone has the right to equal treatment without discrimination based on fifteen grounds, including disability, in areas such as employment, housing and services. This means that persons with disabilities should be able to work, get housing or access services without barriers.

"Disability" covers a broad range and degree of conditions, some more visible such as physical disabilities, some invisible, such as, mental illness. Some conditions may be present from birth, relate to accidents or events, others develop over time. The *Code's* definition also includes situations where a person is perceived or "seen" to have a disability but actually does not have one.[3] For example, an employer does not hire a job applicant because she *thinks* the individual has a mental disorder. It does not matter that the applicant does not, in fact, have a mental disorder. If that person is perceived or "seen" as having one by the employer, it still amounts to discrimination because of disability.

Even when job applicants do have a mental health disability, employers must objectively assess their ability to do the job. They should not rely on perceptions and stereotypes that put up invisible barriers to job opportunities. In fact, a recent Ontario Human Rights Tribunal decision, *Lane v. ADGA Group Consultants Inc. of Ottawa*,[4] upheld the right of persons with a mental health disability to be appropriately accommodated in the workplace under Ontario's *Code*.

The Commission is concerned that certain requirements, policies and practices relating to non-criminal police record checks can have a discriminatory impact on persons with mental health-related disabilities seeking employment. For instance, mental illness may result in non-criminal contact with the police. Under the *Mental Health Act*, police can apprehend people to take them to a hospital for examination where it appears that their mental disorder may result in serious bodily harm to themselves or others.[5] In many cases, the individual or a family member may have contacted the police for help.

Such non-criminal contacts with police are also recorded in police databases and may be kept for a number of years. In some cases, they may never be removed. While contact with police may have been made under emergency circumstances, the information collected may later be disclosed through a police record check. When that happens, the record can have a lifelong impact when that individual tries to apply for a job, take up volunteer activities, enroll in a course or look for housing.

As providers of services to the public, police organizations are covered by the *Code*. This includes the full range of their services, including police record checks. For this reason, police need to ensure that their responses to a request for a police record check do not result in discrimination by unnecessarily disclosing information relating to mental health. Checks that go beyond what is reasonably required can stigmatize persons with mental illness, wrongfully reinforce a stereotypical link between mental illness and criminality, and result in further marginalization of the community.

A related area of concern is the growing tendency of organizations to ask applicants and volunteers to consent to police record checks. Some organizations may legitimately request police background checks, such as when hiring employees or volunteers to work with vulnerable people. However, in many other cases, while the organization may prefer to have the information as a screening tool, it may not actually be necessary for the job at hand, and therefore not a reasonable and legitimate requirement.

This can create more invisible barriers. In addition to the potential for negative impact on persons with a mental health disability, police record checks may also have a discriminatory impact on individuals identified by other *Code* grounds. As the Commission's work on racial profiling demonstrates, some groups are more likely to have had contact with police. For example, studies indicate that racialized and Aboriginal persons are disproportionately represented in the criminal justice system[6]. If they also experience mental illness, members of these groups may be doubly disadvantaged.

It is therefore essential that individuals and organizations understand the implications of requesting police record checks and ensure that they are only asking when such information is genuinely required. Police services should also ensure that they gather sufficient information about the reason for the police check, and be aware of their responsibilities under the *Code* when assessing and disclosing information about non-criminal contacts. If police record checks are not requested, conducted and used properly, they can give rise to human rights concerns.

The Commission continues to receive inquiries from community organizations and government agencies about this issue as well as related human rights complaints. Recognizing the lack of understanding of this issue, the Commission held a public consultation in February and March of this year to get feedback from individuals and organizations on a new draft policy addressing mental health discrimination and police record checks. The consultation will lead to a final, approved Commission policy that will provide individuals and organizations with the information they need to know about:

- mental health-related concerns that arise in the context of police record checks;
- how Ontario's *Human Rights Code* applies; and
- the responsibilities of all parties involved to ensure that their policies and practices are not discriminatory.

Over the years, the Commission has developed a number of policies that provide direction on how to remove barriers and address a wide range of human rights issues. A new policy on issues facing persons with mental illness related to police record checks adds to that body of work so that "written" rights become "lived" rights.

*Barbara Hall is Chief Commissioner at the Ontario Human Rights Commission.

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POLICE RECORDS CHECK AND VULNERABLE POSITION SCREENING

Lisa Heslop,[*] Eldon Amoroso,[**] Sherry Joyes[†]

Background

All organizations that provide services to vulnerable people have a responsibility to appropriately screen their employees and volunteers to ensure their clientele are safe. Failure to screen applicants may place the service recipients in dangerous situations. One step that organizations may take to protect their clientele involves a Police Record Check and Vulnerable Position Screening (PRC/VPS). The purpose of the PRC/VPS is to ensure that the prospective employee does not have any history of behaviours, documented by the police, which are believed to put vulnerable persons at risk.

Currently, there is no standardized process that guides police agencies as to how PRC/VPS are conducted. Practices of individual police services across the province vary widely. Some police services provide the applicant with a printed list of all police involvement regardless of the nature of the contact. Other police services give the applicant a vetted list of occurrences; however, this has been done without clear guidelines as to what information should be excluded. The London Police Service's (LPS) historical practice involved making a determination of whether or not 'information of concern' existed in a person's police record. The determination of what constituted 'information of concern' was guided by the intuition of the record screening staff. Often, non-criminal involvement with police due to mental health crises was considered 'concerning.'

In February 2004, a formal complaint was filed with the Ontario Human Rights Commission (OHRC) against the LPS regarding the discriminatory nature of the PRC/VPS practice. The substantive complaint was that the process amounted to discrimination because:

- The police service indicated that there was 'information of concern' wherever the individual had non-criminal involvement with the police resulting from a possible mental illness.
- If the applicant elected to not provide the employer access to the PRC/VPS (because it contained confidential information that was not relevant to the position), the employer may become concerned that the individual had something relevant to hide and not hire him/her.
- No clear guidelines existed regarding what constituted 'information of concern.'

Ontario Human Rights Code

The Ontario Human Rights Code is a provincial law that gives everyone equal rights and opportunities without discrimination on different grounds, including disability and record of offences, in specific areas, such as employment.[1] The Code determines what information employers have the right to access. Where an employer can demonstrate a bona fide occupational requirement for a position which can not be accommodated, the employer may discriminate against an individual who does not meet that requirement. The Code permits an employer not to hire a person if she or he has a criminal conviction if the nature of the conviction is relevant to the job qualifications. For example, if a person had been convicted of sexual assault, the employer of a daycare may consider the conviction when deciding to hire this individual.

London Police Service Protocol for PRC/VPS

In 2006, the LPS developed a framework which clearly defined how information contained in the police record would be vetted for PRC/VPS.

The model is grounded in the *Human Rights Code*. Employers or applicants complete a PRC/VPS form which identifies potential risks inherent in a specific position. Risks are identified by describing the vulnerable clientele that the agency serves, the environment in which services are provided, the types of activities employees will be engaged in and the relationship between the employee and the vulnerable clientele. Employers or applicants are asked to describe any other factors that are relevant for consideration, such as access to the clients' money or medications.

Based on the information provided on the VPS form the LPS record screening operators search the applicant's police record to determine if relevant information exists. What constitutes relevant information is dependent on the position applied for, but is strictly limited to documented behaviour which has caused harm to a vulnerable person. The record screening operators may also consider documented behaviour which creates significant risk of causing harm to a vulnerable person. For example, if an individual applies for a position which requires driving a vulnerable person, the applicant's driving record would be considered relevant for consideration. The LPS would indicate that relevant information may exist for an individual who had a history of unsafe driving irrespective of whether the individual caused harm. Using this criterion, an apprehension under the *Mental Health Act* would never be considered relevant and would never be disclosed to an employer. The PRC/VPS form is generally returned to the applicant. No specific information is disclosed to employers regarding the individual's involvement with the police; however, applicants who have information which may be relevant are provided with the opportunity to have their employer accompany them to the LPS headquarters to review the finding. In addition, there is a defined appeal process that the applicant can request for a small fee.

Employers and applicants are advised that this process does not make hiring recommendations.

PRC/VPS Evaluation

In the spring of 2006, the LPS introduced the new protocol to the various agencies that provide services to vulnerable persons by offering an orientation seminar which was attended by over one hundred agencies. Seven months later, the LPS surveyed agencies, applicants and record screening operators to determine the protocol's validity and efficacy. It was concluded that the protocol met its objectives on all counts and was favourably received by all users.

The roll-out strategy employed by the LPS was very successful and was an integral component of the protocol. Employers who attended the orientation seminar highlighted the benefits of having attended the seminars in the evaluation. Having an informed employer was clearly demonstrated to result in a better outcome for all stakeholders. Employers reported that the new protocol was both easy to understand and to use. They appreciated that the new protocol gave them a more tailored, consistent and faster return. They also reported that they had a much better sense of how to interpret the results of the PRC/VPS.

How much weight employers gave to the PRC/VPS in making their hiring decision is a very important issue. Concern that employers would automatically disqualify a candidate when the PRC/VPS indicated that relevant information may be contained in the applicants police record the LPS to ensure employers were educated regarding the limitations of PRC/VPS. Employers need to understand that the LPS does not make recommendations on hiring decisions. Most employers who responded to the survey evidently understood these limitations. Only 8% indicated that they would disqualify a candidate based solely on the PRC/VPS. This number was reduced by half (4%) for those employers who attended the introductory seminars. This finding was further validated by the applicants. Almost half (47%) of those applicants whose PRC/VPS indicated 'relevant information' reported that they were successful in obtaining the position they had applied for.

Most PRC/VPS applicants completed the application form without assistance. As with the employers, they found the form easy to understand and complete. They believed that the findings of the PRC/VPS were both relevant to the position that they had applied for and that the LPS had made a fair assessment of their police involvement. As was predicted, this finding was not as strong for those applicants who had relevant information on file; however, only 17% of those applicants indicated that they believed the findings were either unfair or had been based on irrelevant information.

The protocol was shown to have increased the efficiency of the Record Screening Unit and rated high on internal consistency by Records Screening Operators. In addition, the new protocol increased the Records Screening Officer's confidence in determining what information was relevant to an application and made it easier for them to explain findings of concerns to applicants.

Issues for Consideration

The general public has little awareness of the depth of information contained within police databases or what information is considered when a PRC/VPS application is submitted. There is a pervasive misperception that information is purged more quickly than is actually the case and that a historic criminal conviction automatically disappears after a number of years. Despite the fact that applicants sign a statement authorizing a search, they may not have been aware of the parameters of the search to which they were agreeing. As a result, applicants with information of concern or historic criminal convictions may have been surprised by the PRC/VPS results. Care should be given to ensure that applicants are provided with adequate information about the process and are advised of their right to appeal the findings.

Finally, the determination that relevant information may exist within the applicants' record based on unsubstantiated allegations remains a challenge for the PRC/VPS protocol. There are individuals who victimize vulnerable people but are never convicted of an offence for a wide variety of reasons, such as the victim does not want to proceed with a charge. These types of applicants have a documented pattern of behaviour within the police record that never results in a conviction. It was felt by some applicants that these unsubstantiated allegations should not have been given any weight; however, there unmistakably remains a need to evaluate each case based on its individual merits. By not permitting police services to raise a cautionary flag to employers about individuals who have a history of victimizing our most vulnerable citizens contributes to putting vulnerable individuals at risk.

Conclusion

The London Police Services PRC/VPS protocol was implemented in response to issues arising from a human rights complaint that alleged the screening practice was discriminatory towards individuals with mental illness. The new PRC/VPS protocol eliminated employer access to extraneous information, thereby ensuring that individuals who had contact with the LPS due to mental health concerns were not unduly discriminated against. In no circumstance would a *Mental Health Act* apprehension be considered relevant information to be disclosed. By all measures, the new PRC/VPS protocol is a significant improvement over the previous LPS practice.

The importance of police records check and vulnerable position screening cannot be overstated. Vulnerable individuals who depend on agencies to provide services must trust that the agency has used all information at their disposal to protect them from those who could cause them harm. At the same time, the utmost care is required to ensure that individual applicants are not unduly discriminated against in this process and that employers are not permitted access to information that is not relevant to the position in question. Instituting a protocol to guide police services in appropriate screening is imperative to striking this balance.

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[1] R.S.O. 1990, c. H.19.

POLICE RECORD SEARCHES AND PRIVACY ISSUES: BALANCING PUBLIC SAFETY, SECURITY AND PRIVACY

John Swaigen[*]

In recent years, it has become increasingly common to request applicants seeking jobs, opportunities to volunteer, educational opportunities, and admission to many trades and professions to provide a "police background check" as part of the process of screening for suitability.

Police record searches, also known as "police background checks," "criminal record checks" or "criminal reference checks," are often required by law or practice where an applicant or incumbent in a position of trust will have regular or unsupervised access to vulnerable individuals such as children, the disabled, and the elderly or where he or she will have access to money, confidential information, or vulnerable property.

Benefits and problems of police background checks

Protecting vulnerable individuals from harm or employers from theft is an important goal. Indeed, a company, agency or school that fails to protect itself, its clients, and the public by checking an applicant's background runs the risk of being negligent. Failure to collect relevant information may result in physical or psychological harm to coworkers. It can also result in financial loss to an employer or agency or to its clients through fraud, theft or property damage, and may expose the employer or agency to civil liability for harm that might have been foreseen and prevented had more information been disclosed.

On the other hand, providing too much information – that is, information that is unnecessary for determining suitability or incorrect – may violate the privacy of an applicant and lead to unfair rejection. A police report may provide irrelevant but inflammatory information or the information provided may be inaccurate or incomplete. In fact, applicants have been denied access to accommodation, employment, and other important benefits and opportunities, based on incorrect or inflammatory information in police record check reports.

Requiring an applicant to authorize police to report information to a prospective employer without any opportunity to challenge inaccurate or irrelevant disclosures violates one of the fundamental principles of privacy protection – the right to control access to one's own information and to correct errors in it. Yet this happens frequently.

Unfortunately, what information may be disclosed in a police record report and how that information may be used by prospective employers, landlords, and others, is largely unregulated in Ontario and in most other Canadian jurisdictions.

The way police background checks are conducted in Ontario, and likely in other parts of Canada, creates a risk of substantial and harmful violations of the privacy and human rights of applicants. Individuals often assume that a police background check will be limited to convictions for criminal offences. They think that if they have not been convicted of a crime or other serious offences, the report will come back "negative." In fact, police databases may contain information about *any* contact with the police, whether as a complainant, victim of crime, potential witness, suspect or "person of interest," or as someone charged with a crime (even if charges were subsequently dropped or an acquittal resulted). In many cases, any of this information may be included in a police record check report, regardless of whether it is relevant to a candidate's suitability for a position or eligibility for a benefit.

For example, in 2006, the Information and Privacy Commissioner/Ontario (IPC) received two similar complaints about practices of the Toronto Police Service from individuals who were denied positions interacting with vulnerable individuals.[1] In both cases, the individuals had been detained under the *Mental Health Act*,[2] which permits police to take an individual to be assessed by a physician if he or she is acting in a manner that gives the police reason to believe that the person may cause harm to herself or others.

When the two organizations to whom the individuals had apply learned from the police that their files contained information about the individuals, both organizations denied the applications without inquiring further about the nature of the information.

Although both individuals had signed a consent authorizing the police to disclose information in their records to the organizations, the consent form did not make it clear that this included mental health records. As a result, IPC investigator Mark Ratner ruled that the disclosure by the police did not comply with section 32 of the *Municipal Freedom of Information and Protection of Privacy Act*,[3] which permits police to disclose personal information where the individual to whom it relates *has identified that information in particular* and consented to its disclosure.

Police practices discriminate against people with a history of mental health problems, a fact reflected in the intervention of the Ontario Human Rights Commission into these police practices and the establishment of the Mental Health Police Records Check Coalition in 2007. However, the victims of these practices are not limited to the mentally ill.

A San Francisco couple was prevented from adopting a child because a background check report stated that the husband had a criminal record, even though he had "never been in any kind of trouble, ever for anything." Only after the family hired a lawyer and began preparing a lawsuit did the husband receive a letter from the state Justice Department apologizing and acknowledging that he had no criminal record.[4]

Similarly, in 2007, a job applicant in New Zealand won $12,500 in damages before a human rights tribunal against police who revealed sealed details of a failed court case to a prospective employer. [5]

The limited ability of privacy and human rights laws to prevent problems

While privacy laws place some constraints on what information may be disclosed and how it is used, they are not always well designed to deal with this particular kind of problem. In his June 2006 report *Controlled disclosure of criminal record data*, the Privacy Commissioner of Victoria, Australia found:

> Although privacy laws generally restrict collection, use and disclosure of criminal records and other personal information to what is necessary and relevant (such as to lessen or prevent a serious threat to public safety or public welfare), the legislation is easily trumped by other laws that mandate police checks regardless of necessity or relevance, or expressly dispense with any discretion in how such information might be used.[6]

Human rights laws may also provide protection in some circumstances. For example, as a result of complaints about the London Police Service disclosing mental health information, the Ontario Human Rights Commission issued a letter in 2007 to all police forces in Ontario urging them to adopt a "risk-based" approach to disclosure of mental health information.[7]

The Commission stated that if a police background check reveals information relating to mental illness, the police should "not indicate that the person has or had mental illness, that there is reason for 'caution' or 'concern,' or that there was other, unspecified contact, leading an employer or other organization to assume that the person presents a risk. Instead, police services should undertake an individualized assessment, taking into account the nature of the police contact, the essential duties of the specific position and an evaluation of the actual degree of risk associated with the person's placement in that position."

While human rights laws may protect individuals from discrimination on grounds such as illness, gender, race or religion, they do not assist other individuals such as the San Francisco couple who faced adoption difficulties from disclosure of inaccurate information or from revealing information that may be irrelevant to a risk analysis, such as old convictions for minor offences.

What are the police and government departments that supervise them doing about the problem?

In 2006, David Simpson, Acting Director of the Psychiatric Patient Advocate Office, wrote to both the federal Minister responsible for the RCMP and the Ontario Minister responsible for the OPP and municipal police, complaining about the disclosure of mental health information in police checks. Both senior levels of government disavowed any responsibility for how police carry out this function.

However, police departments themselves recognize that there is a problem in how they carry out background checks. In 1999, the Ontario Association of Chiefs of Police produced guidelines for police departments to use in carrying out background checks, which have never been released to the public. The Durham Police, among others, have acknowledged that these guidelines have not resulted in consistent practices among police forces.[8] As a result, the Durham Police and Toronto Police both wrote to Minister Kwinter asking that the provincial government create standards for police background checks. They received the same response as the Psychiatric Patient Advocate Office – not our responsibility. LEARN (the Law Enforcement and Records Managers Network), a committee of the Ontario Association of Chiefs of Police, began a review of these guidelines in 2006 that may lead to greater consistency.

What have other jurisdictions done?

Other jurisdictions have recognized this concern by introducing specific legislation to limit what police may disclose in police background checks and set out how the accuracy and relevance of the information can be verified, and what uses recipient organizations may make of the information.

For example, British Columbia's *Criminal Records Review Act*[9] requires specified employers and the governing bodies of certain professions to ensure that prospective employees or practitioners who will work with children undergo a criminal record check. However, employers are prohibited from requiring such a check unless they have made a conditional offer. Although the Act does not explicitly state what information is to be provided by the police, it appears to be limited to convictions and outstanding charges for specified offences.

If a record is found, this does not automatically exclude the applicant from the position. An adjudicator must determine whether the conviction or charge means that the individual represents a risk. If the adjudicator rules that there is no risk, the employer is free to hire the individual despite the record. If the adjudicator finds that the individual does pose a risk, the individual has a right to appeal the ruling.

Britain's *Police Act, 1997*[10] regulates what information may be included in a "criminal record check" report. In most cases, the government will issue a report to the individual to whom it relates, but not to the potential employer. The individual can decide whether to give it to the employer (although the employer would undoubtedly be entitled to take into account an applicant's failure to provide the report). The report will show only "unspent" convictions (a spent conviction is similar to a pardoned conviction in Canada). The report will not show "spent" convictions or cautions. To ask for additional information, an employer must be registered and must have the consent of the prospective employee to receive the record. Only employers who provide services to vulnerable individuals or have substantial security concerns are entitled to be registered. An applicant may apply to the government to correct inaccurate information.

Illinois' *Health Care Worker Background Check Act*[11] has been in effect since 1995. It prohibits nursing homes, hospitals, hospitals and other designated "health care employers" from hiring anyone to care for the sick who has been convicted of committing or attempting to commit certain listed offences. Once the health care employer has made a conditional offer of employment, it must apply to the State Police for a "criminal history record check." The applicant must be informed of the employer's application, has a right to obtain a copy of the report sent to the employer, and has a right to challenge the accuracy and completeness of the report. If the report shows a conviction, the applicant can apply to a regulatory body for a waiver of the prohibition against employment. In deciding whether to permit the hiring despite the record, the regulatory body must consider factors such as: the age of the applicant when the offence was committed; the circumstances surrounding the offence; the length of time since the conviction; criminal history since the conviction; work history; current employment references; character references; and any other evidence demonstrating the suitability of the applicant or indicating that the applicant does not pose a threat to the health or safety of his or her charges.

Conclusion

The increasing use of police background checks to screen applicants for suitability for many employment and volunteer opportunities and eligibility for other positions and benefits has been raising privacy and human rights concerns that are starting to reach news media, tribunals and courts.

While they constitute an important safeguard for public safety and security, police checks also have the potential to unfairly deprive applicants of important benefits and opportunities, and can interfere with their ability to fulfill their potential as human beings or to earn a living.

It is questionable whether privacy and human rights laws alone, as presently constituted, can ensure a proper balance between public safety and personal privacy in deciding what is to be disclosed and how it is to be used.

In deciding how to strike a proper balance, it may be worthwhile to consider the approaches taken by other jurisdictions that have passed laws specifically dealing with police background checks. These laws often specify clearly what personal information may be disclosed and mandate a risk-assessment approach to determining what can be disclosed and how that information may be used. In addition, these laws often provide an opportunity to challenge these decisions on the basis of inaccuracy, irrelevance or unfairness.

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2 R.S.O. 1990, c. M.7.
3 R.S.O. 1990, Chapter M.56.
4 "Mistaken Criminal History Almost Prevents Adoption", KGO TV, California, March 29, 2007 http://abclocal.go.com/kgo/story?section=local&amp;id=5165713.
5 "Police lose landmark job privacy case", Stuff.co.nz February 21, 2007 www.stuff.co.nz/print/3958369a10.html.
6 Office of the Victorian Privacy Commissioner, *Controlled disclosure of criminal record* data, Report to the Attorney General pursuant to section 63(3) of the Information Privacy Act 2000, report 02.06, June 2006, p. 13.
7 Letter from Barbara Hall, Chief Commissioner, Ontario Human Rights Commission, to Ontario Association of Chief of Police, January 19, 2007.
8 Letter from Doug Moffatt, Chair, Durham Regional Police Services Board, to Hon. Monte Kwinter, Minister of Community Safety and Correctional Services, July 13, 2006.
9 [RSBC 1996] Chapter 86.
10 1997 Chapter 50.
11 Ch. 225 ILCS 46/.

RIPPLES FROM STONES THROWN: THE IMPACTS OF DISCLOSING MENTAL HEALTH INFORMATION ON POLICE RECORDS CHECKS

Barabara Brown[*]

Mental illness impacts every aspect of life. For people living with mental illness, these impacts are known deeply. Symptoms, like stones in the river, ripple the flow of life, influencing one's sense of self, employment, relationships, community involvement and family. Societal stigma regarding mental illness, however, is like a stone thrown in the river, resulting in ripples that are often far more damaging. Police policies and practices that report 'mental health apprehensions' on police records checks perpetuate this stigma, creating discriminatory and limiting circumstances for those with mental health issues as they seek employment, school or volunteer placements or when they travel.

Most Ontario police services routinely disclose apprehensions under the *Mental Health Act*[1] on a police records check despite the absence of criminal activity. A police records check is a search of the local police database. Used as a screening tool, it is generally requested by potential employers, for volunteerism or training placements, and at times, by landlords as a securing condition.

If you call 911 to assist a person incapacitated by suicidal actions or psychotic behaviours, the police attend to the call with paramedics, document the encounter as an apprehension, and subsequently report it on any requested police records check. This means that if you're suicidal and call 911, you will end up with a police record.

This policy of disclosure is not mandated by federal or provincial law. It is created by municipal police boards. Only the London Police Service has proactively altered their practice to reduce unnecessary disclosures.

Generally, Ontarians are unaware of this police practice. Upon discovering this information, most people express disbelief, wondering why police report mental illness but no other health issues. For those who unwittingly discover that they or someone they know has a mental health police record, shock comes first, then a myriad of other emotions.

"I was mortified," says one person. Another reports, "I was so embarrassed and ashamed. I didn't really know what it was about. To me, it meant something criminal." The father of a 15 year old shared how the record impacted his son. This young man had successfully recovered from a deep depression and had a new found enthusiasm for life. He returned to school after an extended absence and was volunteering at a seniors' home. When a police records check was required, the young man gave up volunteering rather than share police-reported mental health information, and thus forfeited his high school diploma. The father was devastated to watch his son lose hope and possibilities for his future.

Another person who worked in social services for almost twenty years experienced a severe depression after a series of tragic losses. She attempted suicide and called 911 for help. As a part of her healing, she sought an agency counselling job. She didn't hesitate to sign a police records check request, having done so throughout her career. But this time, something came back, and she had to disclose this information or lose the job offer. She was terrified as she stared into the possibility of losing her chosen career and a substantial part of who she was.

The impact of this practice literally costs people years of their lives. The ripples from the stigma concerning mental illness were powerful enough for one woman to immediately leave a ten year volunteer placement. She voluntarily disclosed her mental health issues to the family with whom she volunteered (with no negative consequences) although police checks were not required. When the agency learned she had a record, she resigned. "It is the fear of what will happen if you tell your story...I internalized it – it was about me and I had done something wrong. Prior to getting help for my mental illness, I had isolated myself. It took a very long time to...seek help, and so [after the police record disclosure] I reverted back. It really put me back into the illness." She stayed home for six months before deteriorating so badly she was taken to hospital and began another five-year inpatient journey. In the experience of those affected, this practice clearly undermines a person's capacity to get and stay well.

The fear of disclosure is so high in part because the risk of discrimination and harassment is very real. The cruel treatment of those with mental illness, like the stone thrown by the bully, often lands hard, creating huge waves. We know that some people give up employment opportunities due to the fear of negative outcomes from disclosure. We also know that others have their employment offers rescinded. Some people feel unable to pursue schooling, while others are disbarred from performing student or volunteer placements. The practice is prohibitive to people moving forward in their lives.

A further effect of police records checks is the denial of entry into other countries, particularly the USA. One person was separated from her family and detained at USA customs when her psychiatric diagnosis was discovered. Her police record of non-criminal mental health apprehensions is kept on file with American officials and was enough for entry to be permanently denied. This has resulted in her missing critical work-related conferences and trainings.

One person reflects: "It seems to me there are many very silent, very invisible people who face making this disclosure." We do not currently have statistics on the number of people affected, nor the number subjected to discriminatory treatment once they disclose.

The ripples go beyond the individual. Family members of those with mental illness wish they had known about the police records check practice. They feel guilty that in order to get immediate help for their loved one, they are creating a future barrier. Some say they might have made different decisions about seeking care or the method of intervention. This practice holds the potential of preventing people from accessing support when they or a family member need it.

The impact of unnecessary ripples in the water also appear at a broader level. Deterring people with mental illness from contributing to society creates a significant cost to our society. The current police practice prohibits and discourages people from working, volunteering, or furthering their education, the system itself creates a financial drain on government and familial supports.

With increased early intervention programs encouraging people to seek treatment for mental health, a growing number of people are at risk of being impacted by this police practice. As one woman said, "It feels like a set-up – seeking care, then being slapped backwards with the police record. Why wouldn't that same level of organization [health care/government] step in to deconstruct the barriers that exist in the system? This policy is creating a pool of people limited not by their mental illness, but by a police practice that contravenes our own laws."

One of the frustrations is the appalling absence of legal options. If someone has a criminal conviction, they are entitled to apply for a pardon which, if granted, will remove convictions from their criminal record. But, a person with a mental health apprehension notation on their police record does not have this opportunity. Thus, once something is on your record, it can remain there for many, many years (e.g., in Toronto, it is five years plus the year of incident.)

Theresa Claxton of the Ontario Association of Patient Councils states: "We live in a nation that promotes the rights and responsibilities of every citizen living in this country, yet again and again, people with a mental disability are discriminated against. We need to address [police reporting mental health apprehensions] as a human rights issue."

This police practice is alarming. It takes away people's hope. It stalls them in their recovery efforts and exacerbates mental illness symptoms. It limits employment, volunteer, school placement and travel opportunities. It exposes people to harassment and discriminatory behaviours as they struggle for wellness. The practice devastates individuals and families, creating ethical dilemmas for those in immediate support roles not wanting to create future hurdles for a loved one. The current police practice creates an unnecessary barrier in returning to actively contributing to society. This in turn substantially burdens the national social net of health care, social services, income and housing support. The cost is real in terms of quality of life for the individual and society. It is real in terms of dollars and cents. It is a cost that we could easily stop paying. These are ripples that do not need to exist.

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1 R.S.O. 1990, c. M.7.

ON-THE-FLY: MOBILE CRISIS INTERVENTION TEAMS

Kevin Masterman[*]

"It's Simon." I'm going to jump."

It's the phone call Constable Jimmy Braund dreaded after the mobile crisis intervention team (MCIT) officer had given his number to a client. After the line went silent, Braund immediately set out on the road with Registered Nurse Eric MacMullin in search of the man they had brought to hospital three times that week for severe depression. He had given their number to Simon hoping he'd call him for help but his crisis had reached a boiling point.

Soon after setting out, Braund spotted a puff of smoke. It was the first signal that Simon had followed through on his plan. Braund had caught the smoke out of the corner of his eye and followed it to the Dowling Avenue bridge where Simon straddled a girder above the railway tracks after lighting his shirt on fire.

"I blasted him with a fire extinguisher," says Braund. "I put him out and then tried to talk some sense to him and thankfully we had built up a rapport from the last week and he took it to heart."

Two other officers arrived to help bring Simon off the bridge, allowing Braund to handcuff himself to the bridge to help guide Simon in. They brought him to St. Joseph's Hospital where staff placed him into their detox program. He has since called to tell them how well he was doing. Braund also connected Simon to Toronto Police Service Constable Kim Turner, of the Aboriginal Peacekeeping Unit, to find him further supports.

Toronto is one of several Canadian cities with MCITs. The MCIT partners a Toronto police officer with a mental health nurse for on-the-fly medical expertise in response to calls for emotionally disturbed persons (EDPs). These individuals can be suicidal, delusional, caught in a horrific flashback, lashing out wildly or cowering in terror. Their language may be garbled. Their physical strength can be enormous.

The thing is, most of them are sick. They're not criminals. The MCITs have been more effective than ever with an expanding role in Toronto. "It gets victims the help when they need it, and gets access to both the health care and justice systems at once," said Toronto Police Service Deputy Chief Kim Derry of Divisional Command.

Derry, who oversaw the implementation of the first MCIT in the city, expects the teams to be available across the province by year's end. "It serves the public at large well, it serves the health system well and it's good value for the money," said Derry.

The program was launched in November 2000 following the recommendations of several high-profile coroners' inquests, including that of Edmund Yu. Yu, a 35 year-old man with schizophrenia, was fatally shot on a bus in 1997 after refusing to drop a hammer he had raised over his head when confronted by police.

The MCITs are now found in: 51 and 52 Divisions in partnership with St. Michael's Hospital; 11 and 14 Divisions in conjunction with St. Joseph's Health Centre; and 41, 42 and 43 Divisions which pairs up with the Scarborough Hospital, which includes the Grace and General campuses MCIT nurses and officers are called to work with emotionally disturbed people to assess whether the person needs further treatment at hospital or a referral to another community agency or if the person should be charged criminally.

Primary Response officers need to be first to the scene to ensure the safety of MCITs but can then clear the call and head back to the road. "We're getting busier but our apprehensions are going down," said Registered Nurse Eric MacMullin, of the burgeoning five-plus calls per day each Scarborough team fields and the lessening need to hospitalize the people they encounter.

"It's always very interesting, a different story everyday," said Braund, who was drawn to the work because he felt comfortable dealing with EDP calls while working in 11 Division in the past. He figures he's an easy person to talk to as well. "Most people are very fun to deal with – a friendly lot."

14 Division Constable Linda Falasca, the second half of officers attached to the unit, says emergency services are often sought in times of desperation or depression.

Many people the team deals with don't have much money or knowledge of how to get help and end up at hospitals. Others simply need someone to talk to and reach out to 9-1-1 with suicidal thoughts rather than other supports. "If we can avoid a visit to an emergency room by offering referrals to community resources, we will."

MacMullin stressed the importance of calling MCITs right away, before officers make a decision to bring a patient to hospital. "This gives us the opportunity to assess the living conditions of the individual, which can have a significant impact on what options we have." Sara Kirkup, Scarborough Hospital regional mobile crisis programs manager, said that mental health professionals benefit from having an officer on hand to apprehend a patient, while officers benefit from having other alternatives to bringing the patient to the hospital for evaluation. "Without a mental health professional, police officers' options are limited," she said. Kirkup said the team allows for better decisions to be made without the necessity of a hospital visit. "It ensures the continuity of care."

The teams benefit from officers and nurses who are committed to the program. "They are really interested in the work," said Kirkup.

Constable Paul Rowe, who partners with MacMullin and the two other registered nurses in the program, said the goal is to relieve the strain mental health calls place on the primary response officers by finding long-term solutions.

"Our motto is 'no repeat customers'," said Rowe, of trying to find the right supports for the person or to reconnect that person with existing supports. "If we refer them properly and give them the help they need, we won't see them again."

Rowe said he was interested immediately in the team because he has seen mental illness in his own family. "It gives me empathy for the people who are suffering from mental illnesses. I want to make a difference in their lives," said Rowe, who believes he's suited to the job because of his patience. "It can be very frustrating but you have more time to spend with the person."

At a call, MacMullin gets a sense of a person's illness and how they are being treated. He asks himself if the person can be referred to another agency or needs to be taken for an assessment at the hospital. "The worst thing to do is overtreat a person," said MacMullin. "You don't want to activate other treatments if there is support already in place."

The team was then notified about Frederick,"* who had been making calls to 9-1-1, worried that his neighbour was intent on hurting him. Rowe and MacMullin assess if the man needs further care. He welcomes them in, eager to discuss his concerns about the neighbouring apartment.

The apartment hangs heavy with the stale smell of smoke and is coated with grime and dirt. Frederick discusses his worries about the neighbour, as he sits beside a table with a host of medications to control his bi-polar disorder.

MacMullin is satisfied he is getting care from his doctor and Frederick agrees he'll make an effort to stay away from the neighbour and that he may have been over-reacting. "We talked about medication, as well as the affect of alcohol on his medication," said MacMullin, noting alcohol negates the effect of the drugs.

Both Rowe and MacMullin said the time they take on proactive calls like these with a person will save primary response officers from responding to inappropriate 9-1 1 calls later on. "We can connect them with community services and ensure they have been diagnosed and are being seen by a doctor."

The other huge benefit to having a nurse on the front lines is their ability to navigate the health-care system. Having a team of regular members gives emergency room staff familiar faces to deal with on a regular basis.

Registered nurse unit coordinator Dru Skeates said the team is more efficient because they are more familiar with mental health care, how hospital and emergency rooms function and the resources in place. "The information we get from them is more concise and direct," said Skeates. "We talk the same language." She said the team is able to relate to patients better and understand what care they receive. "We often get them a lot calmer," said Skeates, of the team bringing in patients. "It's decreased the number of violent and aggressive patients."

Scarborough hospital social worker Mike McNally said the MCIT is a great system. "They give us more information and more clout in terms of making an assessment or apprehension," said McNally.

MacMullin said emergency room nurses, doctors and security have become familiar with the team and an integral part of the speed with which the team operates.

"We put a lot of effort into maintaining good relationships with the hospital staff," said MacMullin.

"They have a great impact on our efficiency."

When asked about his thoughts regarding the expansion of MCITs, MacMullin stated, "Its one of those rare win-win situations. The police win by saving time and resources, the hospital wins by utilizing resources more effectively and most important, the patient wins by gaining access to community resources that are more appropriate and efficient to their needs."

***Names changed to protect the identity of the individual.*

* Kevin Masterman, is a writer/photographer for the Toronto Police Service Public Information Unit.

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CRISIS REDUCTION: MOBILE CRISIS INTERVENTION TEAMS, NOT TASERS

John Sewell*

There's not much of a mystery as to why we hear of more and more interactions between police officers and people in crisis – more and more people are experiencing crisis every year.

The big problem is that too many people can't get the necessities of life in Canada. There has been no national program to build affordable housing for 15 years, and no such programs in Ontario for more than a decade. As boarding and rooming houses disappear in the rising real estate market and the shortage of affordable modest accommodation grows, a serious crisis is created for people with a limited income. Some people break under the strain. The housing situation is so bad that two-thirds of the people in Ontario jails are awaiting trial there because they haven't got a place to call home.[1]

The situation is not helped in Ontario by the loss of many industrial jobs and the opportunities and income those jobs provided. Welfare rates are far below the poverty line, affordable child care spaces are hard to find, and schools have never recovered from the Mike Harris years. No wonder so many are in crisis.

And who attends to those in crisis? Often the first person on the scene is a police officer, called to an address where someone is acting strangely. Officers are trained to take charge of situations and they do it by yelling at people to put their hands in the air, or lie on the ground, or whatever. This is about the worst possible way to approach someone in crisis, and the results too often are disastrous, as they were for Otto Vass and Edmund Yu, to name just two people who died at the hands of police in this kind of situation.

Now, one of the favourite responses of the police when faced with this situation is to pull out a taser and give the individual an electrical shock. In spite of all the assurances provided by Taser Inc., the weapons' manufacturer, this is not a harmless tool. In Canada, 19 individuals have died after being tasered.[2] Some say being shot with the taser had nothing to do with the death; others say it had everything to do with it.

To retrain police to respond entirely differently seems to be asking for the impossible. Police have been told for more than 10 years they need a new approach to people in crisis but for the rank and file that seems to be elusive. Fortunately, a different way of responding is being used in Toronto and it seems to work pretty well, even if it's not perfect.

The Mobile Crisis Intervention Team (MCIT) pairs a plain-clothed police officer and a mental health nurse. When police identify a call as involving someone experiencing a mental or emotional crisis, the team is sent out. The team has an extraordinarily successful record of de-escalating and defusing these situations to the benefit of everyone, not least the person in crisis. It's a very useful addition to traditional police work since it puts the front-line officer directly in touch with those who can solve a complicated problem that's scary and unpredictable for an officer.

Sadly, the teams do not work in all divisions, and they are only on call from 1 pm to 11 pm. Chief Bill Blair of the Toronto Police Service says the teams involve no extra cost to the police, and they save considerable time for the police given the skills of the team in calming people. There's a cost to the hospitals for the nurses, but surely the savings of people not being injured or killed far outweigh those costs.

One would think the police would be doing everything in their power to ensure that this service is expanded to 24 hours per day and throughout the city, but apparently that's not the first priority. Instead, the police think the key is to equip every officer with a taser.

Until April 2006, tasers were only available in Toronto to members of the Emergency Task Force, the elite and highly trained police squad adept at negotiating tricky situations. Then, the Toronto Police Services Board authorized front line supervisors in three divisions to be equipped with and to use tasers.

In 2006, tasers were deployed in Toronto in 156 instances, and in 147 of those cases, the person was perceived to be in crisis or to have a mental disorder. It's clear who tasers are aimed at – almost entirely people in crisis. Interesting, at 51 Division, where tasers were not available to front line officers - who instead rely on a MCIT - tasers were used by the Emergency Task Force only 4 times.

At Divisions 42 and 52, where both tasers and MCITs are available to front line officers, tasers were used in 66 instances.[3]

Obviously, the technology of the taser appears ready to trump the softer and more effective innovation of the MCIT. This means people in crisis are at risk of being injured or killed by tasers, as has happened in other cities.

Chief Blair's desire to put a taser in the hands of every front line officer in Toronto (at a cost of $8.6 million) has been restrained by the provincial government, which so far has refused to pass the necessary regulation to allow tasers to come into general use in Toronto or the rest of the province. It's good the province has refused to act, but one fears that police pressure might get a taser into many hands.

We'd be smart as a society if we took steps to first reduce the number of people in crisis. Building affordable housing is one step; improving income support is another. Those steps should begin immediately and will take time to be implemented. In the meantime, we should expand the MCITs, not just in Toronto, but in all police forces across the province. Having police work in partnership with community agencies (and hospitals) is a change for some police forces, but it is long overdue.

What we don't need is to give a taser to every front line officer. As we've seen in many other jurisdictions, police use tasers not to replace a gun, but to replace other effective ways of interacting with people, such as talking to them. Falling for the taser trick is a real threat to people in crisis in Ontario. Police need to implement the better approach shown by the Mobile Crisis Intervention Team.

*John Sewell is a former mayor of Toronto, and a member of the Toronto Police Accountability Coalition – www.tpac.ca .

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1 Ministry of Community Safety and Correctional Services.
2 Amnesty International (Canada).
3 Report by the Toronto Chief of Police to the April 2007 meeting of the Toronto Police Services Board.

MENTAL HEALTH POLICE RECORDS COALITION: SYSTEMIC ADVOCACY AS A CATALYST FOR CHANGE OF POLICE PRACTICES

Nicole Zahradnik (Canadian Mental Health Association, Ontario),* Theresa Claxton (Ontario Association of Patient Councils), Jane Letton (Community and Legal Aid Services Programme) and David Simpson (Psychiatric Patient Advocate Office)

Approximately 20% of Canadians will experience a mental illness at some point in their lives.[1] For some, this may result in non-criminal contact with the police under the *Mental Health Act.*[2] Persons with mental illness or perceived mental illness may come into contact with the police for a variety of reasons, many of which are not criminal in nature. For instance, when a loved one is in crisis, a family's first reaction is to often call for help by calling the police. If the individual is transported to the hospital by the police, this information is included in a police record. Unfortunately, if the individual were to then request a police records check for the purpose of working or volunteering with a vulnerable population, this non-criminal/medical information would be disclosed.

To begin, criminal record checks and police record checks are not the same thing. Criminal record checks show information only about convictions a person has received. Information is obtained from the Canadian Police Information Centre (CPIC), which is operated by the Royal Canadian Mounted Police. It is accessible to all law enforcement agencies across Canada and stores information on individuals who have a criminal record for any *Criminal Code*[3] or other federal statute offence. Included are criminal records of persons who have been judged not criminally responsible for an offence because of a mental disorder, as well as individuals with pending criminal charges or those on probation. Criminal record checks are often requested by banks, retailers and other employers who have financial security concerns. No one (except law enforcement agencies) can access another person's criminal record without consent of the person to whom the record relates.

Police record checks are much broader than criminal record checks. A police record check includes a criminal record check, plus a search of the local database maintained by the police agency where the individual resides. A local force may also contact other local police departments in Canada and the United States to obtain information from their databases. Information stored in a local database will relate to any involvement with the police, including: convictions; charges; or information about an individual as a complainant, victim, suspect, or witness to an occurrence, including allegations where charges were not laid. Any contact with the police, in fact, will result in the police recording information relevant to the incident. Incidents relating to the *Mental Health Act* are also stored, including voluntary and involuntary transfers to medical facilities.

Police record checks are intended for individuals seeking employment, school placements or volunteer positions where they will be responsible for the well-being of one or more children or vulnerable persons. The *Criminal Records Act*[4] defines children as 'persons who are less than 18 years of age.'[5] It defines vulnerable persons as 'persons who, because of their age, a disability or other circumstances, whether temporary or permanent, (a) are in a position of dependence on others; or (b) are otherwise at greater risk than the general population of being harmed by persons in a position of authority or trust relative to them.' The *Criminal Records Act* further states that when an individual applies for employment with an employer responsible for vulnerable persons, the employer may request that the police query the pardoned sex offender registry. There is no mention in the legislation of a check for incidents linked to a provincial *Mental Health Act*. In practice, however, these searches have been extended to include information about mental health contacts with police.

Police record checks are used widely by volunteer agencies, schools and employers who are guided by a duty of care for their clients. In other cases, the checks may be used as an additional screening tool, either by the organization itself or its insurer.

With so many local police services across Ontario, there is no standardization among services concerning the coding, retention and release of information. Each Ontario Provincial Police detachment, federal detachment and municipal service has different standards and processes for conducting police record checks. Information requested on the application forms vary; some forces will ask an applicant to list complete addresses for the past three years, while others will request information on the last five or ten years. In addition, there are no universal police policies in place to guide police agencies around issues of disclosure, which means that information is released based on the personal discretion of a commanding officer or records management personnel. Some police agencies will release all information that is found in the record, regardless of the type of position the person is applying for, while other agencies will treat each case individually and make a decision based on the position itself. Furthermore, information may be released to the individual, to the agency, or both, as each police service has different rules and procedures.

Regardless of the inconsistencies and lack of standardization among Ontario police services, releasing information obtained under the *Mental Health Act* is stigmatizing and reinforces the assumed link between mental illness and criminality. It equates incidents where an individual may have behaved in a 'disorderly' manner - which the courts have interpreted to mean behaviour that is to some extent irrational, although not necessarily unruly - with criminal convictions and violence. The fact is that research indicates people with a mental illness who do not have a substance abuse problem are no more likely to be violent than the general population.[6] Including information about police encounters lowers the burden of proof from 'beyond a reasonable doubt,' in the case of a criminal conviction, to 'reasonable and probable grounds,' which is all that is necessary for an apprehension by police under the *Mental Health Act*. An officer can bring someone to a hospital for an examination as long as the person 'apparently' has a mental disorder and has threatened or attempted to harm themselves, has behaved violently or caused someone to fear bodily harm, or has shown a lack of competence to care for themselves. Police must stay with the person until the facility decides whether to admit them. Frequently after evaluation, the individual is simply released and returns to the community.

When someone with a history of mental illness who has had contact with the police is required to complete a police records check, they may be forced into an uncomfortable position - having to disclose their illness in order to explain why the police have 'information of concern,' or to withdraw their application. This situation contravenes the *Ontario Rights Code*,[7] which protects an individual from discrimination in employment (employment has been interpreted to include volunteer positions and school placements) based on their disability. The *Code* requires that, if a potential employee's disability affects his or her ability to perform the essential duties of a job, this assessment can only take place after a conditional offer of employment is made. Not surprisingly, the process of police record checks may act as a disincentive for people with mental illness to attempt to enter or return to the workforce. While the choice to complete a police records check is called 'voluntary,' the likely consequence of refusing to participate is to be excluded from consideration for the position.

In response to this discriminatory practice, in the summer of 2006, the Psychiatric Patient Advocate Office called a meeting with stakeholders to discuss options for change. Several months later, the Mental Health Police Records Coalition was formed to advocate for a record check process that is more respectful of the needs of individuals with mental illness or a perceived mental illness. Goals of the Coalition include: educating consumers, families, stakeholders and police regarding the practice and impact of the release of non-criminal information; advocating for the development of consistent standards for police record searches across the province; and eliminating the discriminatory practice of releasing non-criminal information as part of the police records search process.

Since the inception of the Coalition a fair bit of advocacy work has taken place including various presentations at conferences, print articles, and interviews – all in hopes of increasing awareness about this issue and advocating for change. In addition, letters to various ministries and agencies have been written asking to investigate the issue, one of the many being the Ontario Human Rights Commission. Seeing as the release of non-criminal mental health information contradicts the *Human Rights Code,* the Commission has developed a draft policy to address the ongoing concerns about requirements, practices, and procedures relating to police records checks. The final policy will set out the recommended responsibilities of organizations requesting the checks and of police services in the assessment and disclosure of non-criminal information. The Coalition is pleased to hear that the Commission has taken action on this important issue and will continue to raise awareness about the discriminatory process and work with stakeholders and police services to bring about change, such as introducing a private members bill to seek legislative prohibition of disclosures of mental health records.

[*] Nicole Zahradnik is a policy analyst with the Canadian Mental Health Association – Ontario. She is also a Co-Chair of the Mental Health Police Records Coalition, along with the other co-authors listed.

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POLICE TRAINING: DE-ESCALATING REAL-LIFE SCENARIOS

Bill Blair[*]

Mental illness is a significant public health issue – one that the Toronto Police Service (TPS) treats very seriously.

Often, the very difficult task of responding to incidents involving persons who suffer from mental illness falls to police officers.

Most people who have a mental illness never have contact with the police. But, for those who do, they are often in crisis.

Experts predict that the numbers of people with mental illness will grow exponentially over the next decade.

The lack of sufficiently-funded, community support systems and crisis response services has led to an increased interaction between police and persons with mental illnesses.

Between January 1, 2007 and April 2, 2008, TPS officers attended 12,682 calls for emotionally disturbed persons.

A fairly common public perception is that there is a lack of comprehensive and ongoing training of police officers regarding the recognition of mental illness, and that police are not properly trained in crisis management techniques.

This is not the case.

The police play an important role in responding to, and defusing, difficult situations and in providing support and reassurance.

Many police organizations, including the TPS, have introduced mobile mental health crisis teams in an effort to provide better services to those persons suffering from mental illness.

The community-based Mobile Crisis Intervention Teams (MCIT) partner a mental health nurse with a police officer to respond to incidents involving individuals with mental illness.

The Toronto program, which has universally been accepted and applauded, was launched in November 2000.

Since then, MCITs have been extended to seven additional police divisions. The goal is to expand them across the TPS.

Our officers continue to receive training in how to deal with emotionally disturbed persons, including annual scenario-based training for all frontline officers.

In 2006, the training was expanded to include vulnerable persons and issues surrounding suicide. The vulnerable person component enhanced officers' knowledge and awareness of how to interact with developmentally delayed and other vulnerable persons by teaching them how certain situations can be de-escalated with communication and sensitivity strategies, thereby allowing for both better officer safety and the provision of respectful, appropriate police service.

In 2007, officers underwent specialized training specifically devoted to crisis intervention training.

Today, each and every new recruit is trained on de-escalation techniques based on complex real-life scenarios.

The aim of the training is to enhance officers' understanding of mental disabilities and their symptoms, to increase their knowledge of available community resources and alternatives, and to develop some basic crisis communication skills. When public safety providers are equipped with this information, they are in a better position to effectively resolve future incidents.

I believe that this training will ensure that officers have the knowledge and skills to better identify and meet the unique needs of individuals who are emotionally disturbed or suffering from mental illness.

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*Chief Bill Blair is Chief of the Toronto Police Service.

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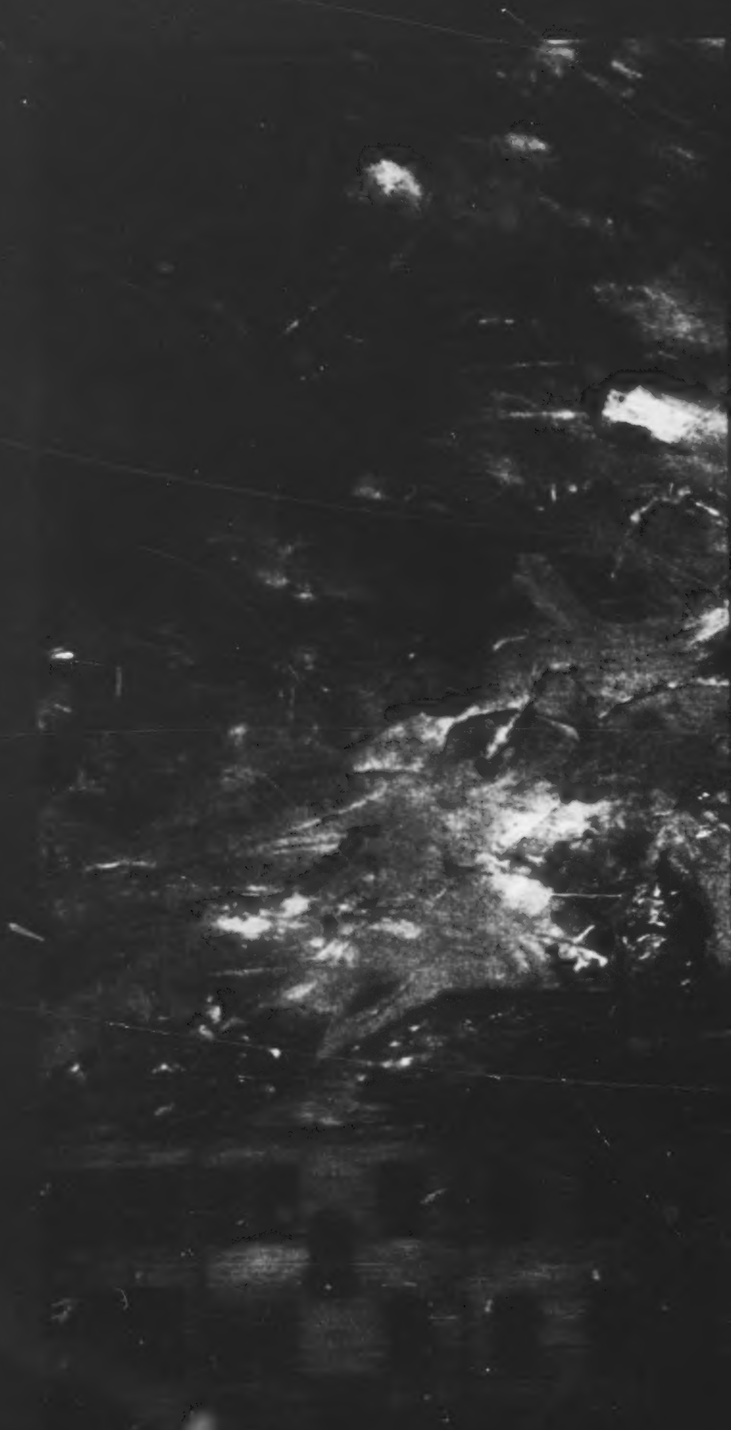

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Advocate Office
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ISBN 978-1-4249-6580-9 (Print)
ISBN 978-1-4249-6582-3 (PDF)